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Short-term, Intensive Neurodevelopmental Treatment (NDT) Program Experiences of Parents and their Children with Disabilities

Debbie L. Evans-Rogers

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Debbie L. Evans-Rogers

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Chairperson of Doctoral Committee: Jane K. Sweeney

Jane K. Sweeney

Doctoral Committee Members: Pat Holden-Huchton

Patricia Holden-Huchton

Pamela A. Mullens

Pamela Mullens

Date: March 27, 2012

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List of Abbreviations

COPM	Canadian Occupational Performance Measure
CP	Cerebral Palsy
GAS	Goal Attainment Scale
GMFCS	Gross Motor Functional Classification System
ICF	International Classification of Function, Disability and Health
NDT	Neurodevelopmental Treatment
OT	Occupational Therapy/Occupational Therapist
PT	Physical Therapy/Physical Therapist
SLP	Speech Language Pathology/Speech Language Pathologist
ST	Speech Therapy
WHO	World Health Organization

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Dedication

This dissertation is dedicated to my family: my mom, Dorothy Evans, who has provided unending support and love to my family and myself, and has always encouraged my brother and me to follow our dreams and our love of knowledge; and to my husband, Dave, the love of my life, and our four beautiful children, Lindsey, Megan, Kristen and David.

Short-term Intensive Neurodevelopmental Treatment (NDT) Program Experiences of Parents and their Children with Disabilities

Abstract

Purpose

While numerous pediatric therapy decisions are made by parents, minimal research has been conducted on parents' perspectives regarding their experiences during high intensity interventions of neurodevelopmental treatment (NDT). The purposes of this study were to: 1. investigate the perceptions of parents of children with disabilities regarding their child's participation in an intense pediatric therapy program (NDT); and 2. examine if differences occur in functional skills of children with motor disability after an intensive NDT program.

Methods

A mixed design of qualitative and quantitative methods was used. Participants included 13 parents/caregivers of children with disabilities and their children (1-17 years of age). To explore parents' perspectives of the intensive program, a phenomenological approach of inquiry was conducted through direct interviews and observations. Intervention intensity was 2-4 hours per day of direct handling for a 1 or 2 week duration. Functional skills were measured pre- and post-intervention using the Goal Attainment Scale (GAS) and the Canadian Occupational Performance Measure (COPM).

Results

Child participants demonstrated significantly improved ($p<.001$) scores on the GAS and COPM pre-to post-intervention with the NDT intensive program. Parents valued the intense format of the NDT program. Seven themes were identified as critical to their children's therapy programs: 1. Positive effects were seen with increased intensity; 2. Expert, compassionate

therapists were valued; 3.Team collaboration was vital; 4. Objective, realistic goals were required; 5. Home programs with teaching were needed; 6. Funding and scheduling were challenging; 7. Children and their families had individualized needs.

Conclusion

A short-term, intensive NDT program consisting of 2-4 hours of intervention daily for 1 or 2 weeks improved functional skills of children with disabilities. Parents highly valued the intensive program and its benefits for their children.

CHAPTER I

Introduction

Background and Significance

In the United States (U.S.), children with disabilities compose 18% of the population.[1] Cerebral palsy (CP) is a common pediatric disability with an incident rate of 2 to 2.5 out of 1,000 live births.[2] Optimal service delivery models for improving function of children with disabilities are an important consideration for parents. Numerous therapy options using different types of intervention of varying intensities are available to parents of children with neuromotor disorders such as CP. Research is needed to examine commonly used interventions of varying intensities and analyze their effectiveness in pediatric physical therapy. Neurodevelopmental treatment (NDT) is a popular intervention strategy for children with disabilities used with varying intensities by pediatric therapists in the U.S. and abroad.[3, 4] Although a variety of delivery models and interventions have been the focus of quantitative research, few studies have been published focused on parental experiences with intervention. Conducting interviews with parents using a phenomenological research design is one avenue for exploring parent's views on intervention programs. This study is novel in using mixed methods to explore an intensive NDT program through phenomenological inquiry and quantitative functional skill analysis.

Many researchers have examined the efficacy of NDT as an intervention strategy without unified consensus on its effectiveness**.**[4-13] Extensive research has been conducted to examine specific intensive therapy regimens such as partial weight bearing treadmill training, strength training, and constraint induced therapy.[14-24] Only four studies in the last 10 years by Tsorlakis,[25] Trahan and Malouin[26, 27] and Bierman[28] used NDT as the direct handling intervention while specifically researching intervention intensity. In three other studies, Arndt,[29] Adams,[30] and Knox and Evans[31] examined NDT without an intervention intensity focus but featured increased intensities in their research designs. No known study has implemented phenomenological methods to investigate changes in function from a parent's perspective after an NDT program. It is important for pediatric therapists to explore options of delivery models of interventions to assist parents in intervention decisions for their children. Themes and analytical differences discovered from this study examined qualitatively through parent's perspectives and quantitatively with functional differences on the GAS and COPM may be helpful to pediatric therapists and parents exploring intensive intervention programs.

Purpose of Study

The purposes of this mixed method research were to 1. explore parents' perspectives regarding their child's participation in an intensive two to four hours a day, one or two week, NDT treatment program; and 2. examine the effects of intensive NDT treatment on functional outcomes utilizing the Goal Attainment Scale (GAS) and the Canadian Occupational Performance Measure (COPM). In this study parent's perceptions are described using a naturalistic, phenomenological approach combined with quantitative data from two outcome measures: the GAS and COPM.

The general aims of the researcher were to examine parent's perspectives regarding their child's participation in an intensive NDT program using direct interviews and to examine if a significant difference occurred in functional motor skills. Intervention of the children in the program consisted of direct, therapeutic handling with functional skills measured weekly pre- and post-intensive NDT intervention using the GAS and COPM.

Research Questions

Research question one (qualitative design) is: “What has having your child participate in this intensive NDT program been like for your family and you as parents of a child with a disability? Research question two (quantitative design) is: Is there a significant change in functional motor skills measured weekly by the GAS and the COPM in children with CP and other neuromotor disorders after receiving a short-term intensive program of NDT therapeutic handling? The null hypothesis is: No difference will be found in subjects after a short-term, intensive NDT program when comparing weekly pre-and post-test scores using the GAS and COPM. The alternative hypothesis is: A statistically significant increase in functional abilities of the subjects will occur after a short-term, intensive NDT program when comparing weekly pre-and post-test scores using the GAS and COPM.

Theoretical Framework

Physical therapy intervention for children has been based on a range of scientific and theoretical frameworks guiding motor development. For many years pediatric therapy was guided by the neural-maturation theory, based on predetermined central nervous system (CNS) structure-function organization and dominance over reflexive behavior.[32, 33] Originally, specific interventions including NDT were based on a hierarchical/reflex model.[34] Sherrington’s reflexive model dominated the scientific understanding in the 1940’s and 50’s when NDT was first described by Berta and Karel Bobath.[33, 34] The central nervous system was thought to be “hard-wired” with higher level cortical control over voluntary movement and more primitive reflexive control in lower centers. Over the years, motor learning information has progressed and the theoretical basis of intervention has evolved to a more encompassing, interactive systems model.[34] Bernstein’s (1967) theory of motor organization based on function, the dynamic systems theory

(DST), and the theory of neuronal group selection (TNGS) all have components important to the theoretical basis of current therapy interventions such as NDT, and to recommendations guiding intervention intensity.[34]

Bernstein's theory of motor organization

Bernstein suggested that movements become more controlled when their "degrees of freedom" are reduced. The nervous system was described as no longer acting as the dictator of the system, but organization occurred with functional patterns depending on the requirements of the body systems. Both the context and the task needed for the behavior were of equal importance.[34] Bernstein's philosophy complements NDT by focusing on the functional task within the contextual factors including both personal and environmental, while improving biomechanical alignment needed to accomplish a task.

Dynamic Systems Theory

Further development of motor control was explained by Thelen and colleagues[34-36] using the dynamic systems theory (DST). The context-specific importance of moving the body to assist with skill acquisition was expanded with DST. Multiple identifiable factors such as muscle power, body weight, joint configuration, arousal, motivation, brain development, and specific environmental conditions were theorized to affect movement initiation and execution.[32, 33] Three key principles of the DST include the following: 1. body systems have the ability to self-organize; 2. each subsystem develops at its own rate within contextual and physical limitations; 3. motor behavior includes transitional states of stability, instability and phase shifts.[34]

The DST places emphasis on the environment and the body systems; two important aspects to consider with effective therapy interventions. Neurodevelopmental treatment philosophy and increased therapy intensity proponents embrace the importance of critically evaluating the body systems. Motor difficulties are a major problem in children with disabilities, and a variety of individual systems can be impaired, affecting functional movement.[34] Sole system impairments or many combinations in the following systems can affect motor function: neuromuscular, musculoskeletal, respiratory, cardiovascular, integumentary, gastrointestinal, sensory, perceptual/cognitive, regulatory, and limbic systems.[34] Children with disabilities often demonstrate a composite of system impairments affecting posture and movement efficiency during functional, daily tasks. During intensive therapy with NDT, intervention strategies are employed after critical analysis of posture and movement behaviors of the children while recognizing multi-system involvement. Direct handling is provided and modified throughout an intervention session while analysis continues of both the effects of posture and movement and system impairments to assist the child with overall function and participation. The DST model includes the basis of many interacting systems working together in an integrated way to accomplish meaningful activities for the individual.[35] By improving posture and movement through optimal biomechanical alignment, pediatric therapists facilitate improved quality and efficiency of movement through continual analysis and modifications of handling procedures. Increased intervention intensity is required for frequent practice and repetition (components of motor learning) to improve posture and movement behaviors and functional abilities driving the system to be more stable and more efficient. In summary, many principles of the DST coincide with increased intervention intensity and NDT philosophy for assisting children with neuromotor challenges in moving more independently and efficiently.[34]

Theory of Neuronal Group Selection

The Theory of Neuronal Group Selection (TNGS) by Edelman[37] may be the optimal theory supporting NDT and intensive therapy. This theory balances the neuro-maturation theory and the DST by adding the notion of dynamic selection through interaction of a.) brain structure-function and development and b.) behavior selection.[32, 33] This theory has three main tenets including: 1. developmental selectivity of neuroanatomical brain formation; 2. experience of movement shapes (strengthens or weakens) selection of neuronal pathways; and 3. formation of unique neuronal maps is based on responses to task conditions and the environment.[34]

With increased therapy intensity using NDT, facilitation is provided using a variety of sensory-motor experiences to enrich the brain's global maps in multiple contexts.[34] Repeated experience is used for strengthening neuronal mapping for increased efficiency of movement. Based on the current demands of the task, past experience, contextual need, and the state of the body systems, the most appropriate neuronal map is selected to complete the functional skill.[34] Therapists using NDT based intervention acknowledge the importance of self-generated movement with optimal alignment to solve motor problems essential to motor learning and motor skill acquisition. Physical handling procedures which improve movement efficiency, influences the neuronal group selection for optimal functional abilities. Increased intervention intensity is required to strengthen the optimal neuronal maps for effective function.

Developmental plasticity is the brain's ability to reorganize in structure or function in response to a change or insult.[38] The brain exhibits plasticity with a lifetime of opportunities for new movement learning. Environmental change and developmental transitions may provide opportunities for brain adaptation.[39] Researchers using NGST advocate the importance of therapy with variable sensorimotor experiences for younger children, and many opportunities for practice of skills for older children with neuromotor dysfunction. In summary, both intensive therapy and NDT intervention for children encompass the DST and TNGS principles of shaping neuronal mapping with many systems working together for the emergence of efficient posture and movement behavior. Repetition of skills and functionally relevant practice should accelerate the acquisition of motor skills.[17, 37]

Importance to Pediatric Science

This study contributes to the current body of literature for pediatric therapy clinicians and caregivers of children with disabilities by expanding understanding of specific intensive intervention options through the following: 1. sharing authentic viewpoints of parents participating in an intensive NDT program; 2. examining functional changes resulting from intensive therapy using two outcome measures: the GAS and COPM; 3. contributing information regarding parent perceptions on home programming and team collaboration; and 4. providing information to other families of children with special needs on intensive NDT programs.

With the importance of evidence-based research in the pediatric therapy clinical practice, a better understanding is needed of parent’s experiences during intensive therapy for their children with disabilities. Due to the widespread use of NDT by pediatric therapists and the increasing interest in intensive therapy, evidence through well designed research is essential to document effective changes in functional outcomes using an intensive NDT format.

Definition of Terms

Operational definitions used for this study include the following:

Intensive intervention: Intensive intervention consisted of direct handling by PT, OT and/or speech therapy provided daily, for a duration of two to four hours per day, for a one or two week length of time. Total amount of intervention time was 10-20 hours/week.

Neurodevelopmental Treatment (NDT): Neurodevelopmental treatment (NDT) is a common intervention strategy used internationally by pediatric therapists for children with disabilities. Please refer to Appendix G and H and Chapter 3 for basic NDT pediatric course information and specific NDT protocol used with this study. Pediatric therapists providing intervention for the study participants were:

- NDT instructors (teaching certified NDT courses)
- NDT-certified (completing 261 hours of continuing education for NDT/Bobath Certificate Course in the Treatment and Management of Children with Cerebral Palsy and other Neuromotor Disorders)
- NDT-trained (taking non-certification NDT continuing education courses)

Parent: Any caregiver or individual bringing the child to the intensive program and participating in the sessions with the child.

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CHAPTER II

Literature Review of Pediatric Therapy Utilizing Increased Intervention Intensity and Neurodevelopmental Treatment (NDT)

Abstract

The purpose of this paper was to review research on the efficacy of pediatric neurodevelopmental treatment (NDT) and intensive physical therapy (PT). The theoretical framework surrounding NDT and increased intervention intensity is outlined. An overview of research on a variety of current therapy treatments used solely and in combination with NDT with increased intensity is included as well as a historical review of NDT literature. Examination of the research designs were conducted with critical review of existing methodological limitations and results. Qualitative studies exploring intervention intensity using NDT were not found; therefore, qualitative studies were reviewed outside the realm of NDT. Initial findings supported further investigation of NDT intervention with increased intensity of therapy using both quantitative and qualitative research. Specific recommendations are provided for researchers interested in future research on increased intensity using NDT intervention for children with disabilities.

Introduction

Research is needed to examine effectiveness of varying intensities of commonly used interventions in pediatric physical therapy. Neurodevelopmental Treatment (NDT) is a popular intervention strategy used world-wide by pediatric therapists for children with disabilities.[1, 2] Evidence-based research is important for optimal decision-making in pediatric clinical practice in today's health care environment.[3-5] The purpose of this article is to review current quantitative and qualitative evidence on the effectiveness of NDT with increased intervention intensity.

The following electronic databases were used in the literature search: Medline, PubMed, Cinahl, Ovid Full Text, PEDro, ERIC, Cochrane Reviews, Google Advanced Scholar, Pediatric section of the American Physical Therapy Association (APTA), American Journal of Occupational Therapy (OT), NDTA Network and EBM databases in OVID. The MeSH (Subject Headings) used included: Bobath, Bobath Therapy, Neurodevelopmental Treatment (NDT), Treatment Intensity, Therapy Intensity, Treatment Intervention, Treatment Outcomes, Treatment Modalities, Pediatric Rehabilitation, Cerebral Palsy, Spasticity, Pediatric Physical Therapy, Pediatric Occupational Therapy, Movement Disorders, Motor Dysfunction, Motor Delay, Gross Motor Function, Qualitative Interviews, and Phenomenological Study-Pediatrics. The studies were included according to the following criteria:

- Intervention intensity was focus of the research.
- NDT was the intervention used to improve motor outcome.
- Subjects were children aged 0-18 years.
- Qualitative research was conducted with interviews discussing disabilities or therapy.
- Study was published or available in the English language.

- References were published as full reports.

Reference lists were also examined and used if appropriate for this literature review. Additional resources were obtained with collaboration from colleagues and pediatric clinical specialists. Forty studies were examined on intervention intensity and on NDT effects with children (Table 2.1). Twenty four of the forty studies were identified on intensive intervention with NDT. Eighteen of the twenty four intensive NDT studies used a minimum of 2 times/week frequency with a minimum duration of 45 minutes (Table 2.2 and Table 2.3 in Appendix K). Nine studies with qualitative designs were reviewed that examined pediatric therapy, caregiver perceptions, individuals with disabilities, or used a phenomenological design (Table 2.4).

The current clinical evidence examining the effects of motor functions using an intensive intervention focus for children with disabilities were divided into three areas:
1. Intensive therapy regimen using alternate modalities; 2. Intensive therapy regimen using NDT combined with alternate therapies; 3. Intensive therapy regimen using NDT. Discussion is focused on specific research methodology including sample size, outcome measures, definitions of terms, and other threats to validity of studies. Summarized clinical implications and recommendations for future research is included.

Background

In the United States, children with disabilities comprise 18% of the population.[6] In this population of children with disabilities, a variety of diagnoses are included such as cerebral palsy (CP) and other neurological conditions, orthopedic conditions, developmental delay, autism and related disorders, and genetic conditions such as Down syndrome.[7] Motor difficulties are a major problem in children with disabilities. Numerous theories for understanding normal and abnormal motor control and motor development have been established. This review focuses on the enablement (ICF) model and NDT theoretical framework supporting intervention at increased intensity.

The World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) is the current classification system focusing on the health of an individual with a disability. The WHO's ICF model incorporates the dimensions of pathophysiology, impairment, functional limitation, disability, and societal limitation.[8] The individual's needs in different contextual realms using an enablement perspective are the focus. The ICF model includes three domains of human function: body functions and structures, activities, and participation. Participation is the result of interactions of the body structure/function, activity demands, and contextual factors with the individual's goals and desires. Using this model, the health and well-being of a child with a disability is taken into account. Pediatric physical therapists (PTs) use the ICF model to enhance clinical reasoning skills and to assist children with a disability increasing their participation. The ICF model recognizes the concept of a disability not resting on an individual attribute, but more significantly affected by societal and cultural acceptance. The disabling process is seen as dynamic with many systems intertwined and with secondary impairments contributing to functional loss.[7]

Theoretical Framework: NDT with Increased Intensity

Neurodevelopmental treatment (NDT), a neurophysiological intervention approach introduced and developed by Karel and Berta Bobath during a period spanning from the 1940s to the late 1980s, is commonly used by physical therapists for children with CP and other movement disorders.[1, 2, 9-11] Neurodevelopmental treatment emphasizes management of secondary impairments and functional limitations of individuals using a problem-solving, hands-on approach.[11] Incorporating the ICF model, a child is evaluated and receives intervention while considering their unique multifaceted environmental and personal contextual considerations applying current theoretical principles of motor control and learning.[11] The handling techniques with NDT address the "whole child", are highly individualized, and require a simultaneous evaluation and modification of handling depending on the results of intervention with each client.[11] Therapeutic intensity including duration and frequency of intervention using NDT varies with each individual child.

The theory underlying NDT evolved from the reflexive/hierarchical models in the early years to "today's NDT" based on current motor learning theories.[11] Evolving motor learning information has shifted the theoretical basis of NDT to a more encompassing, interactive systems model.[11] Bernstein's (1967) theory of motor organization based on function, the dynamic systems theory (DST), the theory of neuronal group selection (TNGS), and current motor learning principles all have components important to the theoretical basis of intensive NDT.[11] Each of these theoretical concepts will be briefly reviewed.

Bernstein proposed that movements become more controlled when their "degrees of freedom" are reduced. The nervous system is no longer considered the dictator of the system, but organization occurs with functional patterns depending on the requirements of the body systems. Both the context for the behavior and the task needed are of equal importance.[11] Bernstein's theory has application with NDT since NDT focuses on the task within the environment, and the biomechanical alignment needed to accomplish a task. Increased intensity provides time for organization of functional patterns.

The context-specific importance of moving the body to assist with skill acquisition was expanded with DST. Three key principles of the DST include the following: 1. body systems have the ability to self-organize; 2. each subsystem develops at its own rate within contextual and physical limitations; and 3. motor behavior includes transitional states of stability, instability and phase shifts.[11] The DST places more emphasis on the environment and the body systems; both assumptions the NDT theory embraces. Neurodevelopmental treatment intervention strategies directed towards preventing additional secondary impairments, decreasing existing impairments, and improving biomechanical alignment to facilitate improved quality of movement also coincides with the DST.[11] Intervention of increased intensity allows subsystems to organize improving optimal and efficient functional movement.

The Theory of Neuronal Group Selection (TNGS) by Edelman[11,12] may be the optimal theory supporting an intensive NDT approach. This theory has three main tenets including: 1. developmental selectivity of neuroanatomical brain formation; 2. experience of movement shapes (strengthens or weakens) selection of neuronal pathways; and 3. formation of unique neuronal maps is based on responses to task conditions and the environment.[11] When utilizing an intensive regimen of NDT, repetition with facilitation is provided using a variety of sensory-motor experiences to enrich global maps in multiple contexts.[11] Therapists using NDT acknowledge the importance of self-generated movement with optimal alignment to solve motor problems; essential to motor learning and motor skill acquisition. Handling which improves movement efficiency influences the neuronal group selection for optimal functional abilities.

Current motor learning principles stress the importance of repetition of skills and functionally relevant practice, both vital aspects of intensive intervention with NDT, to accelerate the acquisition of motor skills.[12-14] Feedback and feed forward techniques with intermittent schedules also enhance motor learning.

Intervention Intensity: Overview and Definition

Physical therapy for children is often provided as a continuous process beginning from the child's early diagnosis or identification of motor delay.[15] Conventional pediatric physical therapy in the United States (U.S.) is usually provided at a one time per week, one hour per session level, often limited by health care benefits.[16] The standard intervention can range from one to three times per week, for 30 to 60 minute sessions with therapy continued throughout the child's growing years.[17] According to Bierman[18] the trend in clinical practice in the U.S. is toward less intensive intervention, possibly related to insufficient evidence to support physical therapy outcomes. Physical therapists treating children with disabilities need to understand the importance of optimal intervention intensity and techniques for improving gross motor function, mobility and functional independence.

Reviewing current theoretical frameworks and research guiding intervention, increased intensity of therapy intervention appears warranted.[16, 17] Piper et al.[19] supported intensive intervention by suggesting "expecting a one-hour weekly therapy session to have a measurable impact on motor development may be unreasonable."[19(p.222)]

Webster[20(p.601)] defined "intensive" as "highly concentrated; tending to strengthen or increase; tending to give force or emphasis." When referring to therapy with children, "intensive intervention" by the physical and occupational therapist is not clearly and universally defined. Bailes et al.[21] developed guidelines for a pediatric medical setting defining intensive intervention at a 3-11 time/week frequency. Despite guidelines, therapists do not use a definition for "intensive therapy" consistently across therapeutic settings. Intensity can be related to the following:

1. specific interventions (direct handling compared to consultative therapy, or adjunct therapy {e.g. compression garments, therapy suits}; 2. frequency of intervention sessions (one time vs.

four times a month); or 3. specific duration of therapy (one hour vs. three hours per day). According to Olney and Wright[22 (p.640)] "optimal treatment frequency is unknown" often depending on a multitude of variances including age and disability of the child, number of therapies provided and other programming, therapeutic setting, resources available, client and family goals including parental needs and desires, and the child's individual responses to therapy.[22] Piper et.al[19] recommended therapy frequency of a minimum of twice weekly. Motor learning information and current theoretical frameworks guiding therapy intervention corroborate this recommendation.[17, 23-25] Therefore, "intensive intervention" is defined for this study as therapy provided an average frequency greater than 2 times/week consisting of hourly sessions of physical therapy (PT), occupational therapy (OT) and Speech Therapy (ST).

Due to the absence of a clear, unified definition for "intensive therapy", researchers have used varying protocols with this descriptor. As an example, Mayo[26] studied the effects of PT on children with motor delay and CP using NDT with an "intensive treatment group" consisting of only weekly therapy visits. Therefore, if studies were found using the word "intensive" but with less than twice weekly frequency, and if the study was pertinent to this literature review on NDT and intensive therapy, the study was included in this review. Studies with intensive therapy regimen using alternate treatments (other than NDT) will be examined first.

Intervention Intensity Studies

Intervention Intensity Studies Utilizing Alternative Therapy (other than NDT)

Pediatric physical therapists use various intervention techniques with a few specific procedures addressing increased intensity. The focus of this section is an overview of current therapy techniques using intensive regimens: 1. studies providing a background for further research; 2. research based specifically on intensity of intervention and neurodevelopmental treatment (NDT); 3. effects of alternative therapy on intervention intensity with younger and older children, medical procedures, partial body weight supported treadmill training (PBWSTT), and constraint-induced (CI) movement therapy.

Intensive Therapy Regimen with Younger Children

Adequate research exists on the benefits of early intervention (EI) for children aged birth to three years.[27-30] Outcome measures often focus on cognitive changes with intervention provided by a variety of disciplines with less emphasis on specific motor changes with physical therapy. The optimal intensity of therapy to improve function in young children with disabilities is still debated. Three recent studies addressed intensive treatment regimens with gross motor outcome measures and therapy provided by a PT in the early intervention setting.[31-33]

Ustad et al.[31] used a single-subject, multiple-baseline, withdrawal research design (ABABA) to examine the effects of daily intervention with five infants (age five to nine months) newly diagnosed with CP. Daily intervention intensity consisted of two four week sessions, interrupted by 8 weeks of traditional PT consisting of therapy sessions once a week or once every second week. The Gross Motor Function Measure (GMFM-66) was used as the outcome measure with the children assessed every fourth week. One assessor, blinded to the children's intervention intensity group, assessed the children. Intensive physical therapy was provided during 40-60 minute sessions with a 5 day/week frequency using an eclectic therapeutic approach with current Bobath/NDT principles. Functional, meaningful tasks were practiced as part of the therapy regimen. Parents were present during the sessions and compliance was high for all the children (93%). The researchers reported all the children had significant improvement in the GMFM scores when compared to baseline findings. The effect of intensive physical therapy was inconclusive as compared to the traditional therapy. With one child (Child 3), a significant increase during both intense intervention phases was noted compared to the traditional therapy intervention intensity. This increased intensity was not accompanied by a statistically significant change in the GMFM scores. Two children (Child 1 and 4) demonstrated improvement during both intervention phases. The researchers explained this improvement by examining the acceleration in motor development occurring during the intense intervention phase and reporting the children were able to continue practicing new skills acquired during this phase. Two children (Child 4 and 5) showed increases in motor function on the GMFM with intervention. The majority of parents preferred the intensive therapy schedule and reported improved learning of handling skills with frequent therapist-parent contact.

LaForme Fiss et al.[32] determined if group intervention was an effective model for increasing intervention intensity for 10 children (age 13-29 months) with Down Syndrome (DS). The researchers examined the effects of intervention and participation in ten weekly sensorimotor groups (increased treatment intensity) compared to intervention alone (control group) using the GMFM-88 and the Goal Attainment Scale (GAS) as outcome measures. Therapy services were provided individually and the experimental group participated in an additional weekly, one hour group intervention session led by a PT or OT. The group sessions consisted of task-specific practice of skills with sensorimotor-themed activities. Scores were compared at three points during the study: initial assessment, 10-12 weeks post-intervention, and 3-5 weeks post-second assessment. The increased treatment intensity group (participating in the additional sensorimotor group intervention) demonstrated statistically significant ($p<.01$) improvements in motor skill acquisition on the GMFM and GAS compared to the control group. A large effect size on 4 domains of the GMFM and pre-to post-testing on the GAS was found when comparing the increased intervention group to the control group. Limitations of this exploratory study included small sample size, limited control and definition of group activities, and no randomization of group placement.

Kanda et al.[33] studied the effects of long-term intensive therapy with ten infants born preterm (less than 33 weeks and birth weight of less than 2000 g.) with periventricular white matter injury or porencephaly (diagnoses often associated with the later diagnosis of spastic diplegia cerebral palsy). Five subjects received intensive PT (30 minutes or more per session, three to four times daily), and five subjects received no therapy or insufficient therapy. Physical therapy intervention was 52 months and based on the Vojta method. The Vojta method was described as a program employing isometric strengthening with tactile stimulation utilizing extensive parental involvement. The outcome measure for the study was assessments based on the Vojta system including motor milestones such as standing and walking. A statistically significant ($p<.05$) result was found when comparing motor outcomes of the two groups with the group of children receiving the intensive protocol having improvement and sustained motor differences persisting 2.5 years after the study period. Limitations of this study included the small sample size with non-randomization, poorly defined and unclear intervention techniques, and non-standardized testing for outcome measures. Many strong aspects of this study existed including: early intervention, strong parental involvement, medical information comparing clinical findings using magnetic resonance imaging (MRI), long duration of treatment, and increased intensity of intervention.

Intensive Therapy Regimen with Older Children

Bower and colleagues[34-36] documented a series of studies specifically on intensity of intervention for children older than three years with the diagnosis of cerebral palsy. Bower et al.[34] initially performed a withdrawal A-B-A single subject design with children acting as their own controls. Therapy was provided in 3 week increments for a total of 9 weeks with the B period consisting of therapy at an increased intensity (from 1 hour/week to 5 hours/week). The GMFM was used as the outcome measure and skill acquisition at a statistically significant level ($p<.05$) was found during the intensive period of intervention. A randomized controlled trial (RCT) by Bower et al.[35] over a two week period using the GMFM found favorable results for intensive over conventional therapy. The researchers reported the importance of the use of specific, measurable goals for increased skill acquisition with this study. Bower and colleagues[36] expanded their intensity research in a RCT with 56 children with CP to further explore goal-directed and intensive therapy over an 18 month period using the GMFM and GMPM (Gross Motor Performance Measure). They found that intensive therapy (five times/week) produced a trend toward a statistically significant difference when additional covariates of age and severity of CP were taken into account. When conventional therapy (frequency of 2 times/week) resumed during the follow-up 6 month period, gross motor function or performance gains were not maintained. Intensive therapy for this period of time was stressful and tiring for the families with compliance difficulties noted.[22, 36] Increasing the frequency of intervention over an extensive time period may compromise the efficacy.[24] The importance of identifying specific, measurable goals for incorporation into daily, functional activities was emphasized by the authors.[22, 34]

Storvold and Jahnsen[37] used a similar multiple single-subject research design examining intensive, goal-directed motor skills training and combined group and individual sessions for children under the age of twelve with the diagnosis of CP (Gross Motor Functional Classification System {GMFCS} Levels I-IV). The intervention described as “intensive goal-directed functional therapy” occurred over a period of 6 weeks with a total of 18 weeks being explored. A total of ten hours of training occurred per week. Individual goals for each child were set with 4-8 goals total per child. Outcome measures included GAS, GMFM-66, Pediatric Evaluation of Disability Inventory (PEDI), functional hand grips test, fine motor speed and the assisting hand assessment (AHA). The researchers reported positive outcomes with mean goal attainment at an 80.4% level with 29 out of the 35 individual goals reached with the six participating children. Most changes were observed during the intervention period with the children maintaining their individual goal levels six weeks later. Parents reported preferring the intensive periods, compared to more traditional, less frequent therapy sessions.

Medical Procedures

Considerable research has been focused on medical procedures such as botulinum toxin A (BTX-A) injections or selective dorsal rhizotomies (SDR) and the accompanying intensive PT with favorable results.[38] Speth et al.[38] followed children with BTX-A injections and 30 minutes of both PT and OT 3 times/week for 6 months and reported this therapy to be a "relatively intense and prolonged course of rehabilitation therapy" which may have benefited both groups of children studied.[38 (p.472)] McLaughlin et al.[39] followed a PT protocol consisting of 2 hours/day, five days per week therapy with children following a SDR. Statistically significant ($p<.01$) improvements in GMFM scores, lowered Ashworth scale scores, and improved range of motion were reported.

Partial Body Weight Supported Treadmill Training

One intervention of interest to researchers provided with high intensity for children with CP is partial body weight supported treadmill training (PBWSTT).[12, 40-44] Mattern-Baxter[44] examined recent research literature on gross motor function, balance, gait speed and endurance in children with CP. Of ten articles reviewed, six studies provided evidence suggesting intensive and prolonged PBWSTT is a safe and effective alternative treatment to improve gait speed, endurance, and balance for children with CP. Of interest regarding frequency of intervention, the most significant improvements were found with high-intensity intervention programs (e.g. 6 times/week for 2 weeks).

Ulrich and colleagues[12, 40, 45] conducted a number of studies investigating the effects of intensity using treadmill training in infants with Down Syndrome (DS). Ulrich, Ulrich and Collier[45] initiated research on seven 11 month old children with DS and found the infants with DS could produce alternating steps on a treadmill long before demonstrating the ability to walk independently. Ulrich et al.[40] found in a four year randomized clinical trial (RCT) of infants with DS using treadmills in their homes 5 days per week for 8 minutes a day, increased independent walking was found at a statistically significant ($p<.05$) rate when compared to a control group not using treadmill training. In a study presented at the III Step Conference, Ulrich et al.[12] used a RCT of 30 infants with DS receiving intervention beginning at 10 months of age comparing higher-intensity treadmill training to lower-intensity treadmill training. Infants with DS in the higher-intensity group attained independent walking at a statistically significantly ($p<.05$) rate compared to the control group, progressing faster and stepping more than the lower-intensity group. The researchers concluded intensive treadmill training for infants with DS complemented regularly scheduled PT intervention and can be used to facilitate motor milestones at an earlier mean age, reducing motor delay in the infants. Increased intensity of intervention using PBWSTT has also been the focus of research in infants with other diagnoses.[41]

Bodkin et al.[41] investigated treadmill training in a case report on a child with a Grade III/IV intraventricular hemorrhage (IVH) following a premature birth at 29 weeks. Intensive therapy conducted three times per week was incorporated into regular PT intervention using treadmill training for a total of 23 weeks using the Alberta Infant Motor Scale (AIMS) and videotape analysis as outcome measures. In this case report, the child demonstrated more mature stepping patterns when compared to stepping trends in infants with neuromotor disabilities. Further research continues to be recommended on optimal training parameters and age of onset for PBWSTT intervention in infants and children with varied diagnoses. Similar to PBWSTT, Constraint-Induced (CI) movement therapy is an intervention used by pediatric therapists and found frequently in literature on intervention intensity.

Constraint-Induced Movement Therapy

Constraint-induced (CI) movement therapy was initiated in 1995 for adults with hemiparesis from cerebral vascular accidents (CVA).[46] In adults with hemiparesis, movement and use of the hemiparetic upper extremity (UE) was promoted by bivalved casting of the unaffected extremity and facilitated use of the more-impaired, weaker extremity through intensive training. Taub et al.[46] investigated CI therapy with a randomized, controlled clinical trial of 18 children with hemiparesis from CP. The therapy consisted of intensive training using behavioral shaping for 6 hours/day compared to 2 hours/week during a 21 day period. Outcome measures included the Emerging Behaviors Scale (EBS), the Pediatric Motor Activity Log (PMAL), and blinded ratings of the Toddler Arm Use Test (TAUT). Researchers found statistically significant gains when comparing pediatric CI therapy participants to the control group in the EBS ($p<.01$), the PMAL ($p<.01$), and the TAUT. Treatment gain effects were maintained at 3 and 6 months of follow-up with a small, non-significant, decline in the PMAL 3 and 6 month scores compared to 3-week post-treatment performance scores.

Gordon et al.[47] expanded this research by studying changes using CI movement therapy with twenty children separated into two groups: “younger group” age 4-8 years, (n=12), and an “older group” age 9-13 years, (n=8) with hemiplegic CP. Intensive movement therapy consisted of wearing a sling on the noninvolved UE for 6 hours/day for 10-12 consecutive days.

Structured practice with both groups consisted of an average of 35-36 hours of structured practice (5.5-5.7 hours per 10 days during the intervention) with both shaping activities and repetitive-task practice during play and functional activities. Outcome measures included the Jebsen-Taylor Test of Hand Function and subtest 8 of the Bruininks-Oseretsky Test of Motor Proficiency (BOTMP). Environmental, quality of movement of UE use and impairments were also documented. Significant ($p<.05$) improvements were noted in both groups with improved hand-movement efficiency and environmental functional limitations of both younger and older children with hemiplegia. These researchers point out the importance of practice and movement, and suggest CI movement therapy is effective for both younger and older children with hemiplegia.

Strength Training

Damiano and colleagues[48-50] reported favorable results with intense physical exercise programs involving strength training for children with CP. In a systematic review on strength training, Pippenger and Scalzitti[51] identified insufficient clarity in the research because outcome measures did not include functional activities in the 11 articles reviewed. Damiano cautioned "since strengthening is only one aspect of physical function… training programs that focus only on that aspect are limited in their effect on function.[52 (p.1537)] Although studies on strength training often used intensity parameters, the priority and remaining focus of this literature review is research on changes in motor functional outcomes related to intervention intensity.

Intensive Intervention Utilizing NDT Combined with Other Therapy Regimens

A few research studies have compared combined therapy regimens of NDT and other approaches.[53-55] In a study by Bar-Heim et al.,[53] the efficacy of Adeli suit treatment (AST) was compared to NDT. Twenty-four children with CP (Gross Motor Function Classification

System -GMFCS Levels II-IV) were treated for 4 weeks with an intensity of two hours/day, 5 days per week. Outcome measures used were the GMFM-66 and the mechanical efficiency index (EI_{HB}) during stair climbing. Although the aim of the study was to investigate whether using the AST compared to NDT would have greater improvements in motor function and mechanical efficiency, statistically significant ($p<.05$) improvements were found using either intensive physical therapy regimen. The researchers reported support for more intensive therapy (both AST and NDT) for children with CP to improve the acquisition of motor skills. Other reports using suit treatment incorporate intensive therapy regimens often conducted 5-6 days/week, with 4-6 hours per day for a 3-4 week duration.[56, 57]

Kerem et al.[54] researched the effects of Johnstone pressure splints (JPS) combined with NDT intervention compared to a control group receiving only NDT. Thirty four children ranging in age from 36-82 months with the diagnosis of spastic diplegia participated in the study. Outcome measures included range of motion (ROM) by goniometric measurement, spasticity evaluation using the Modified Ashworth Scale (MAS) and somatosensory evoked potentials (SEPs) of the posterior tibial nerve. Intervention consisting of NDT was described as “according to Bobath’s motor developmental criteria” with sustaining postures, balance activities and ambulation training described. Intervention of both groups was at a frequency of five days/week for three months. The researchers found statistically significant ($p<.01$) improvements in both groups on ROM, improvements in posterior tibial nerve SEP latencies (higher in the control group) and greater improved scores rating spasticity with pressure splints combined with NDT using the Modified Ashworth Scale (MAS). Although both groups received NDT intervention and demonstrated improvement, a criticism of this study is the lack of outcome measures demonstrating changes in meaningful, functional abilities.

Law[55] compared a regular OT program with a program using intensive NDT and casting in 52 children 18 months to four years of age with CP and upper extremity (UE) involvement. The regular OT group received therapy ranging from a minimum of monthly to a maximum of weekly. The intensive group received therapy twice weekly consisting of NDT for 45 minutes with a 30 minute daily home program and using bivalved UE casting for 4 hrs/day on 2 separate occasions. The Peabody Developmental Motor Scales (PDMS)-fine motor section, Canadian Occupational Performance Measure (COPM) and Quality of UE Skills Test (QUEST) were the functional outcome measures used in this study. No statistically significant differences were found between the two treatment groups. A statistically significant difference was found with average scores on all the outcome measures in both groups increasing over time. A limitation of the study was excessive absences in the experimental group; the average therapy received by the intensive group was less than 2 times/week (children averaged receiving only 1.5 times/week therapy in the intensive group). Functional outcomes were the focus of therapy for the group receiving traditional OT, and the importance of functional goals compared to quality of movement (one of the goals of the intensive group) is now more clearly understood. The use of a discriminative measure (PDMS) compared to a reliable functional outcome measure or a goal (such as the GMPM per the researcher's discussion) is a further limitation of this study.

Pediatric NDT Literature

NDT: Definition

Neurodevelopmental treatment (NDT) is a neurophysiological treatment approach commonly used today by pediatric therapists when treating children with CP and other movement disorders.[1, 2, 9, 11] This technique was introduced and developed by Karel and Berta Bobath during a period spanning from the early 1940s to the late 1980s.[11, 58] The NDT theory evolved from the reflexive/hierarchical models in the early years to the NDT today based on current scientific principles of motor control and learning with components from both the dynamic systems theory (DST) and the theory of neuronal group selection (TNGS).[11, 13, 25, 59, 60] Intervention using NDT focuses on preventing additional secondary impairments, decreasing existing impairments and functional limitations of individuals using a problem-solving, hands-on approach.[11, 61] The child is evaluated and treated using detailed analysis of posture and movement behaviors assessing multi-system involvement of the body. The child's unique multifaceted environmental and personal contextual considerations are examined following the WHO's ICF model.[8, 11] Therapists using NDT have advanced training and work collaboratively with individuals, family, caregivers, other therapists, and physicians to facilitate functional independence. Though researchers studying the effectiveness of NDT have been without a unified consensus,[10, 62] many studies have found favorable functional improvements using NDT.[9, 63-65] In the next section a brief historical review of pertinent NDT research studies is presented with both supporting and non-supporting evidence for NDT and discussion of methodological concerns.

Historical Overview of Pediatric NDT Literature

The effectiveness of NDT is without unified consensus and continues to be debated.[58, 62, 64] Due to the many variables in each child with neurological challenges, research on intervention effectiveness is challenging.[66] The many confounding variables within each child with neurological challenges such as differing ages, types or degrees of involvement and classification of CP, co-morbidity factors, and other co-existing interventions complicates NDT research.[7, 66, 67] Neurodevelopmental treatment, like most motor therapies, is not delivered in a standardized manner.[58] The handling techniques with NDT address the "whole child", are highly individualized, and require a simultaneous evaluation and modification of handling depending on the results of intervention with each client.[68] Lack of operational definitions and variability in intervention may partly explain why Brown and Burns[62] systematically reviewed the efficacy of NDT and found inconclusive evidence in the research. Additionally, Ottenbacher et al.[64] investigated the effectiveness of NDT for infants and children with disabling conditions by reviewing 37 studies; concentrating on 9 specific studies quantitatively (meta-analysis). Ottenbacher et al.[64] concluded subjects receiving NDT performed slightly better than those control-comparison subjects not receiving the intervention.

Eight earlier studies (previous to the last 10 years) with therapists using NDT at a frequency minimum of two times/week frequency reported positive results.[69-74, 79-80] (Tables 2.2 and 2.3) One study by Mayo[26] in 1991 specifically focused on intervention intensity. Mayo's[26] research compared weekly vs. monthly intervention over a 6 month period utilizing NDT. Mayo[26] performed a RCT with 29 subjects ranging in age from 4 to 18 months allocated in one of two treatment groups: intensive (weekly visits) or basic (monthly visits of one hour duration). Individualized home programs were provided to parents of both programs. All the children included in the study were identified with delayed or abnormal acquisition of motor skills; 26 of the 29 children subsequently were later diagnosed with cerebral palsy or other motor delays. Intervention was provided by therapists trained in NDT with suggestions given to parents for positioning, handling and stimulating the children to assist them with purposeful activity during daily routines. The intensive group had the added opportunity in therapy to follow a more detailed program to meet the specific therapeutic goals. A composite of seven instruments assessing a wide spectrum of motor development was used including tests for gross and fine motor skills, primitive reflexes (four were assessed), postural reactions, mental development (the Bayley scale of infant development), abnormal movement patterns, and activities of daily living. The mean initial measure on each instrument of the two treatment groups was calculated. An aggregated index score of motor development was derived from a composite of the seven instruments. Each treatment group's (intensive and basic) initial and final aggregate index scores of motor development were then compared. When the researcher accounted for the child's age, prematurity, and mother's education, she concluded children with motor delay achieved greater improvements at a statistically significant level ($p<.01$) with intensive weekly physical therapy using NDT compared to a basic physical therapy program with monthly revisions.[26]

Other studies have had less favorable outcomes using NDT.[58, 66, 75, 77] Palmer[75] reported the use of infant stimulation to be superior to NDT using the Bayley Scales of Infant Development (Bayley) as an outcome measure in a 1987 study. Herndon et al.[66] examined twelve children with CP before and after an NDT course using videotapes, and goniometry. The evaluators, both physicians and therapists, were unable to tell the difference of children's motor patterns between the two films. Both of these studies have had valid criticism of the absence of functional goals set for the children, the narrowed scope of specific movement patterns examined, confounding factors, and inappropriate outcome measures.

The effects of therapy on postural control of children with CP comparing NDT and practice with reaching activities was studied by Jonsdottir et al.[76] No differences were discovered with either intervention, however in 5 of the 8 subjects, trends in improved postural control were noted after NDT.[76] Blauw-Hospers[77] performed a systematic review of the effects of early intervention on motor development. Intervention programs using the principles of NDT where "passive handling techniques have a prominent role"[77 (p.431)] were not found beneficial to motor development. This finding was not surprising because current NDT principles do not include descriptions of NDT as a passive treatment technique; rather the NDT approach is focused on the child's active initiation and participation combined with hands-on, manual guidance.[11]

Various discrepancies in the research continue regarding the effectiveness of NDT.[11] Criticism of past studies include: 1. inappropriate discriminative outcome measures (such as the Bayley Scales of Infant Development) compared to appropriate functional outcome measures; 2. outcomes based on outdated principles of the NDT approach (e.g.: studying changes in reflexes or tone); and 3. invalid or inaccurate information used to describe the intervention approach. (e.g. passive movement). Bierman[18] summarized both positive and negative results in the research on NDT appropriately: "The influence of physical therapy using the NDT approach is difficult to research due to difficulty with heterogeneous sample groups, methodological problems, practical constraints and inappropriate outcome measures." (p.13)

Recent Pediatric NDT Literature with Intervention Intensity Focus

Although many studies included some aspect of NDT intervention (see Table 2.2 and 2.3), only four studies incorporated NDT as the direct handling method while specifically researching intervention intensity (excluding earlier reviewed study by Mayo[26]). These four studies will now be reviewed.

Tsorlakis et al.[63] examined the effectiveness of intensive NDT intervention by investigating changes in gross motor function using the GMFM with two different intervention intensity levels: two vs. five times a week frequency for a period of sixteen weeks. Thirty-four children ranging in ages from three to fourteen years with the diagnosis of CP (GMFCS Level I-III) were randomly assigned to a control (2 times/week frequency) or experimental (5 times per week frequency) group. The intervention was based on current principles of NDT using an individualized approach for each child. Each pediatric therapist had over 10 years of clinical experience and was NDT certified. Blind assessments (with high intra- and inter-rater reliability; .997 and .994 respectively) were performed with each child pre- and post-intervention using the GMFM guidelines. Although improved gross motor function of the children was found at a statistically significant level ($p<.05$) with both intensities using NDT intervention, the children receiving the greatest intensity of intervention (Group B-5 times/week frequency) had the larger improvement in motor abilities at a statistically significant level ($p<.05$) when compared to the control group (Group A-2 times/week frequency). The researchers reported support for the efficacy of NDT for improving gross motor functional abilities such as walking and stair climbing because both groups (a total of 30 of the 34 children) demonstrated improvement in functional abilities. Further support for NDT intervention at greater treatment intensity was provided through this research, and intensive NDT intervention showed a greater effect on children's gross motor function. "This conclusion justifies the notion for more intensive NDT in CP."[63(p.744)]

Although this research demonstrated adequate statistical power, design questions have been raised due to the randomization assignment of the intervention groups. The researchers addressed concerns regarding the absence of a non-treatment control group due to ethical reasons and cautioned on generalizing findings to children with CP without a spasticity component.[63, 78]

Trahan and Malouin[24, 79] performed two studies contributing to the research of intense NDT intervention for children with CP. First, a longitudinal study was performed over an eight month period monitoring changes in gross motor performance using the GMFM as the outcome measure.[79] Fifty children ranging in age from 12 to 79 months with the diagnoses of spastic, athetoid, spastic-athetoid or ataxic CP were included in the study. Physical therapy intervention was provided for 45 minutes at a twice weekly frequency with individual sessions based on the NDT approach. The children were divided into three groups corresponding to topography of impairment: quadriplegia, diplegia or hemiplegia. Each subject was evaluated three times using the GMFM: once at baseline, then at four and eight months. All three groups demonstrated statistically significant improvements ($p<.05$) at four and eight months within each dimension and in total scores of the GMFM. The children with the greatest impairment (quadriplegia) had the lowest motor performance when compared to the other two groups (diplegia and hemiplegia). This research supported the longitudinal use of the GMFM to detect changes in motor function of children with CP. A limitation of this study was the therapists assessing the children were also treating the children. Since the study's purpose was to monitor changes over time and not to compare intervention, blinding was not essential. Inadvertently, the researchers lend support for biweekly therapy with motor changes detected even in the more severe CP population.

Trahan and Malouin's[24] second study addressed intensive therapy effects through a multiple-baseline, single subject design of five subjects with severe CP (GMFCS Levels IV and V) ranging in age of 10 to 37 months (mean age 22.6 months). The therapy intensity level was 4 times per week for four weeks compared to 8 weeks without therapy during a 6-month period and the outcome measure was the GMFM. Physical therapy consisted of individual 45 minute sessions with direct handling based on the NDT approach. Occupational therapy was also provided simultaneously in a schedule similar to the PT. During the "no therapy" phase, parents were given general advice without specific therapy suggestions or home programming. The more intensive, intermittent regimen of therapy resulted in statistically significant ($p<.05$) improvements in the GMFM scores of 3 of the 5 children with all 5 participants improving total GMFM scores. All children retained motor skills during the two 8 week rest periods. This research supports the feasibility of using short intensive therapy periods followed by longer rest periods to optimize motor skills of severely involved children with CP. Of interest, compliance was very high during the intensive intervention periods. A criticism of the study is absence of a control group to compare motor improvements after the treatment regimen with motor function changes from maturation.[24, 78]

Bierman[18] recently published a case report supporting the effectiveness of an intensive NDT program for a child with spastic quadriplegia and dystonia. A five ½ year old girl served as the subject in this research over a five month period. The subject received PT 3-4 hours per day, in conjunction with OT and speech therapy 1 hour/3-4 times per week, and 4-6 hours/week of aquatic therapy. An expert NDT instructor provided the intensive physical therapy regimen. Functional outcomes included positive transition from a Level 5 to a Level 3 on the GMFCS with a total of a 33% increase in scores on the GMFM. Multiple system impairments (neuromuscular, musculoskeletal, and respiratory) demonstrated change; and improved posture and movement patterns were noted with gains in functional independence evident. This case report has positive clinical implications; however, caution is required for generalizing findings to all children with CP due to the lack of controls in case study designs.

Although recent studies by Arndt,[9] Adams,[80] and Knox and Evans[65] examined NDT without an intervention intensity focus, increased intervention intensities were noted in their research designs. Arndt et al.[9] evaluated the efficacy of NDT using a dynamic co-activation trunk protocol to change gross motor function in infants 4-12 months with posture and movement difficulties. The GMFM-88 was used as the outcome measure to evaluate the motor effects after 10 one-hour intervention sessions were received over a 15-day period. The authors found a statistically significant improvement ($p<.05$) using the GMFM-88 pre- to post-test in an

NDT-based protocol group as compared to a parent-infant play (PIP) control group. One major conclusion from this study was initial support for sequenced trunk co-activation intervention compared to generalized play activities for infants with posture and movement difficulties. Other recommendations included direct handling by therapists specialized in population-specific intervention (e.g. in this study- with infants), high-frequency, short duration sessions, and task-specific interventions.

Adams et al.[80] used an NDT course to examine changes in gait of forty ambulating children with CP. Intervention consisted of one-hour sessions at a frequency of two times/week for six weeks. Direct handling focused on facilitating gross and fine motor function while strengthening muscles with active participation of the child. Twelve sets of pedographs were documented for each child to examine pre- and post-gait changes with intervention. Statistically significant ($p<.05$) changes were reported in the following gait parameters: stride and step length, foot angle, and velocity. Base of support and cadence did not show statistically significant changes but increases (trends) in these dimensions were observed in all participants. The researcher noted children with spastic diplegia CP seemed to benefit most from the intervention, and support for efficacy of NDT intervention was reported.

Knox and Evans[65] used both the GMFM and the PEDI as outcome measures for functional abilities in their study of 15 children (age 2-12 years) with CP. A repeated-measure design was conducted surrounding a 6 week block of time in an NDT course. Bobath/NDT therapy was provided for 75 minute sessions with a minimum of 3 times/week frequency. All 15 subjects demonstrated statistically significant improvements ($p<.05$) in GMFM total scores for motor function and PEDI self care and caregiver assistance total scores following the NDT therapy. Knox and Evans[65] used a supplemental parent questionnaire in addition to the quantitative outcome measures of the research. Although questionnaires may contribute additional information, the questions are often close-ended and can lead respondents in certain directions not allowing more accurate answers.[81] A study employing open-ended questions exploring NDT intervention using a qualitative research method with a phenomenological research design has not yet been reported.

Related Studies Using Qualitative Methods

Many studies using the qualitative method have been used in research outside the realm of NDT (Table 2.4).[82-90] A similar, current study by Christy et al.[90] involved parent, therapist and child perceptions of an intense program using strengthening and functional activities combined with use of an Adeli suit. A phenomenologic methodology (grounded theory approach) with interviews was used by the researchers; similar to this study. Five themes emerged including improvements in motor function, confidence, independence and participation. Although goal attainment for the children was rapid, two negative findings were increased stress of the caregivers and fatigue of the children participating in the program.

Women with developmental disabilities were the subjects of research by Siporin and Lysack.[87] Similar to this study, in-depth interviews were performed and transcribed, field notes were taken, data was analyzed for emerging themes and conclusions were written from these themes. A similar qualitative methodology to this research was also used by Cohn, Miller and Tickle-Degnen[86] when exploring parental hopes for occupational therapy (OT). The data were analyzed using the grounded theory approach, and interviews 45-60 minutes in length using a semi-structured interview guide were performed. Cohn[83] used a collective case study approach examining parents' perspectives of OT using a sensory integration (SI) approach. Data were collected through parental interviews, similar to this research, but data were analyzed with reflexivity using grounded theory methods. Anderson and Spencer[88] used a phenomenological approach with individuals with HIV/AIDS to investigate their experiences and how each individual represented the illness. Data analysis was performed examining written transcripts with meanings formulated from significant statements found in the interviews and clustered into themes.

In physical therapy research, Greenfield et al.[89] used a qualitative design to explore the meaning of caring from the perspectives of physical therapists with less than one year of clinical experience. Seven novice therapists were interviewed using a phenomenological approach. Interviews were audio taped, transcribed and later reviewed by the novice therapists with the data analyzed for emerging themes using Creswell's[91] methods, similar to this research. Glumac[85] also used phenomenology when examining the perceptions of caregivers of Guatemalan children with disabilities receiving donated wheelchairs.

Discussion

Definitive research does not exist on the optimal intensity and length of pediatric therapy required for the best functional outcomes.[24, 33] The 40 articles included in this literature review of intervention intensity and NDT support intervention with increased intensity while advocating further research. Historically, NDT research has been inconclusive, but positive results were found when increased intervention intensity was used with NDT and also with other procedures (e.g. equipment placed on the child as with the Johnstone splint, Adeli suit, UE casting) or during specific activities (CI movement therapy or PBWSTT). Clear support of NDT is found in specific studies directed at high intensity NDT intervention.

Arndt[23] documented researchers studying NDT intervention with at least twice weekly frequency resulted in significant or positive trends in favor of NDT compared to intervention frequency less than twice weekly. Trahan and Malouin's[24] findings support increasing intervention sessions from two to four times/week over a 4 week period for young children with severe impairments. They reported improved (83% to 93.1%) parental compliance with the more intense format. Parental compliance during the therapy regimen to assist with practice and motor learning is often required.[24]

Factors including age of children, quality of program, and parental involvement influence therapy effectiveness. Greater intensity of therapy intervention may be especially beneficial with early learning of motor skills.[17] Physical therapy is often more intense initially when a child is young;[22] and early intervention has been found to be beneficial for young children to facilitate motor outcomes.[30, 77, 92] Active parental involvement with intervention has been found to be important.[93] Sharkey et al.[93] was a proponent of early intervention due to plasticity of the nervous system when using correct components of movement, improved compliance in therapy of younger children, and more parental support in younger children. Ramey and Ramey[29] and Kanda et al.[33] concluded high-quality programs that are more intensive with parent and children participating actively and regularly produced the greatest positive effects developmentally

Appropriate outcome measures including validated and standardized assessments to use for children with CP are additional factors.[65] Historically, reliable research was questionable since valid and reliable measures for evaluating change due to interventions were limited. Campbell[94] discussed the need for research on parameters of motor development that can be affected by PT such as the effects on deformities and functional performance. Many earlier studies used outcome measures not validated or reliable to detect changes from intervention over time. Appropriate functional measures such as the GMFM, GAS, and PEDI are more frequently used in research.[24, 67, 79, 95] Motor goals which are functional and important to the child and the family are required for optimal compliance and motivation.

Researchers expressed concern regarding therapists providing therapy with an intensity high enough to make quality changes with quantifiable differences, but without being exhausting for parents or too tiring for the children involved in the therapy.[24, 36] An intervention regimen with short, intensive periods followed by rest periods has merit.[24] In a health care system continuing to restrict and prohibit payment for intensive pediatric therapy time, clinical practicality of intensive, individualized therapy continues to be a valid concern for practitioners.[96] Inconclusive evidence exists on optimal service delivery models for children with disabilities. Trahan and Malouin[24] suggested further study on conditions of service delivery. This literature review on NDT with increased intensity emphasizes the need for critical guidelines for practice and further research in this area.[18, 24] Due to the absence of qualitative research using NDT with increased intensity, a mixed method design exploring both quantitative and qualitative results is an appropriate research model.

Conclusion

Pediatric physical therapists continue to be challenged by professionals, families, and third party payers to provide the best evidence-based intervention options for children with disabilities. The efficacy among intervention approaches is inconclusive including the optimal intensity for improving functional mobility in children with disabilities. Emerging research with NDT intervention involving increased intensity suggests the intensive NDT approach as a viable option for children with neuromotor disabilities. Intensive, goal-directed intervention by clinicians with specialty training may be necessary to promote optimal motor function.[19]

Rigorous research is recommended with specific intervention protocol descriptions for future replication. Suggestions for further research include: 1. appropriate outcome measures;
2. detailed NDT handling protocol; 3. case reports and research using qualitative methods to grasp the essence of NDT; 4. specific definition of intervention intensity; 5. increased intervention frequency of short periods to promote optimal compliance and minimize parent fatigue; and 6. prioritizing functional, measurable goals important to child and family.

The effectiveness of therapy for children with disabilities continues to be a concern and focus of both therapists and families. Although conclusive evidence on optimal intervention intensity for pediatric clients continues to be challenging due to appropriate sample sizes, heterogeneous subjects and clinically relevant outcome measures, the use of evidence by therapists supporting intervention decisions is critical. Future research using quantitative, qualitative and mixed method designs is needed to investigate optimal NDT intervention intensity.

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Table 2.1 Research Studies Used to Examine Intensive Intervention*

Earlier studies (previous to 2001)	**Studies in last 10 years (2001-2011)**
Carlsen, 1975	**Brown and Burns, 2001**
Scherzer et al., 1976	**Ulrich et al., 2001**
Harris, 1981	**Bower et al., 2001**
Ottenbacher et al., 1986	**Damiano et al., 2001**
Herndon et al., 1987	**Kerem et al., 2001**
Palmer et al., 1988	**Butler and Darrah, 2001 (AACPM)**
Mayo, 1991	**Trahan and Malouin, 2002**
Ulrich et al., 1992	**Knox and Evans, 2002**
Bower et al., 1992	**Bodkin et al., 2003**
Girolami and Campbell, 1994	**Tsorlakis et al., 2004**
McLaughlin et al., 1994	**Taub et al., 2004**
DeGangi, 1994 (part 1 & 2)	**Kanda et al., 2004**
Bower et al., 1996	**Speth et al., 2005**
Law et al., 1997	**Blaw-Hospers and Hadders-Algra, 2005**
Damiano et al., 1998	**Gordon et al., 2006**
Trahan and Malouin, 1999	**Bar-Heim et al., 2006**
Damiano et al., 2000	**Arndt et al., 2008**
Adams et al., 2000	**Ulrich et al., 2008**
	Bierman, 2008
	Ustad et al., 2009
	LaForme Fiss et al., 2009
	Mattern-Baxter, 2009

***Intensive Intervention defined as an intervention with a minimum of 2 times/week frequency with a duration minimum of 45 minutes**

Table 2.2 Research Studies Used to Examine Intensive Intervention* with NDT

Studies previous to 2001	**Studies in last 10 years**
Carlsen, 1975	**Kerem et al., 2001**
Scherzer et al., 1976	**Knox and Evans, 2002**
Harris, 1981	**Trahan and Malouin, 2002**
Herndon et al., 1987	**Tsorlakis et al., 2004**
Palmer, 1988	**Bar-Heim et al., 2006**
DeGangi, 1994 (Part 1& 2)	**Arndt, 2008**
Girolami and Campbell, 1994	**Bierman, 2009**
Jonsdottir et al., 1997	
Law et al., 1997	
Trahan and Malouin, 1999	
Adams, 2000	

*** Intensive Intervention defined as an intervention with a minimum of 2 times/week frequency with a duration minimum of 45 minutes**

Table 2.3: Table of NDT Studies-see Appendix K

Table 2.4 Research Studies Used to Examine Qualitative Designs

Cohn E, Miller L., &Tickle-Degnen, 2000
Camp M., 2001
Cohn E, 2001
Mweshi M, Mpofu R., 2001
Anderson E, Spencer M., 2002
Siporin S, Lysack C., 2004
Glumac L., 2006
Greenfield B, 2008
Christy et al., 2010

CHAPTER III

Research Methods

Study Design

A mixed method research design was used in this study to determine the perceptions of caregivers and functional differences of children with disabilities participating in a short-term intensive neurodevelopmental treatment (NDT) program. The definition of mixed method research from Creswell[1] is: “an approach to inquiry that combines or associates both qualitative and quantitative forms of research. It involves philosophical assumptions, the use of qualitative and quantitative approaches, and the mixing of both approaches in a study.” (p.4) This study combined qualitative (phenomenological) and quantitative (quasi-experimental using repeated measures) designs.

Qualitative methods are appropriately used when a phenomenon is to be researched.[2] The definition of phenomenology is “a science whose purpose is to describe particular phenomena, or the appearance of things, as lived experience.”[3(p.76)] Evidence was derived from the first person accounts of parents participating with their children in a short-term NDT intensive program. Data collection included demographic record review, open-ended questions using a semi-structured interview guide, and field notes. Contributing to the qualitative design, a pre-test/post-test quasi-experimental (quantitative) design was used each week of the intensive program. The children served as their own controls, and no additional control or comparison groups were used. The GAS and COPM were used for pre- and post-testing at the beginning and end of each week of the NDT intervention period. The NDT intervention consisted of direct handling with environmental adaptations encouraging carry over in functional movement and play activities while addressing posture and movement behaviors and impairments by experienced NDT certified and trained therapists.

Study Participants

A convenience sample of caregivers and their children in the NDT intensive program through Partners for Progress were approached to participate in this study. Inclusion criteria for the child participants consisted of the following: 1. age range: 1-17 years; 2. documented diagnosis of cerebral palsy or other neuromotor condition affecting social participation and functional abilities; 3. participation in 70% of the five or ten day intensive program (not missing more than one full day of therapy). Exclusion criteria for participants included the following: 1. diagnosis on the autism-spectrum with a primary somatosensory impairment; 2. insufficient parent participation less than 50% of the five or ten day intensive intervention program.

The final sample included 13 caregivers and 16 child participants (three children participated in both the July and September sessions). All parents and their children registered for the intensive program were willing to participate. A total of nine children were in the first intensive program, and seven children in the second. Because three children had also attended the first of the two intensive programs, their caregivers were not interviewed again. Data were collected pre- and post-intervention on all 16 of the children participating in the intensive sessions. Determination of sample size for the qualitative design was based on saturation of the data using phenomenological research methods with an estimated size of 8-15 interviews and a maximum of 20. Determination of sample size for the quantitative design was based on a power analysis for a directional hypthothesis (one-tailed) with an alpha set *a priori* of .05, a power of .8 assuming a large effect size (Cohen's effect size of .8) using the recommended sample size of 20.[4]

The operational definition of “parent” for this particular study was any caretaker or individual bringing the child to the intensive program and participating in the sessions. All caregiver participants interviewed were Mothers except for one Grandmother. Program applications and participants were taken on a first come, first served basis with inclusion of parents and children representing all race/ethnic groups, socioeconomic backgrounds, and gender. Eleven males and five females participated with the following ethnicities: Caucasian (13), Asian (1), Hispanic (1) and other (1). A ten dollar gift card to a coffee shop was provided to all families participating in the study.

Study Setting

The one and two week tracks of the intensive NDT program were conducted in conjunction with Partners for Progress, a not-for-profit organization in Milwaukee, Wisconsin owned by Linda Kliebhan, PT and Rona Alexander, PhD, CCC, SLP. All children participated in an intensive NDT program of two to four hours/day, five consecutive days for one week; or continuing for two weeks consisting of ten days (with the weekend off). All sessions occurred in two local churches used as the setting for collaborative intervention by Partners for Progress; St. Dominic Catholic Church in Brookfield, Wisconsin (for July intensive); and Gethsemane United Methodist Church in Pewaukee, Wisconsin (for October intensive). All intervention sessions were in individualized rooms or cafeteria in each church. Tape recorded caregiver interviews occurred in separate rooms (or in one instance-the car) from where the children received therapy.

Intervention

Neurodevelopmental treatment (NDT) was the primary intervention used in this study. The following personnel provided the intervention: 1.therapists trained in NDT; 2. certified pediatric NDT instructors (teaching certified NDT courses); 3. certified pediatric NDT therapists (with at least two years experience and completion of a 261 hour continuing education course consisting of didactics, labs, and handling practicums using NDT techniques) (please refer to Appendix H-Curriculum of Basic NDT Pediatric Certificate course; and NDT/Bobath Pediatric Minimal Core Course Content**).**

Neurodevelopmental Treatment Protocol

The intervention used in this study consisted of direct handling techniques learned by experienced pediatric clinicians through NDT instruction. Pediatric physical, occupational and speech therapists learned the NDT techniques through continuing education courses approved by the Neurodevelopmental Treatment Association (NDTA).

A thorough assessment was performed and ongoing with each child, and direct handling was modified throughout each session. Handling consisted of elongation activities of muscles (if needed) coupled with activation of postural muscles and graded midrange control (with muscles activated during transitional movements such as slowly moving sit to standing) during age-appropriate play and functional activities. Emphasis was on optimal skeletal alignment, base of support and center of gravity shifts while providing sensory information and activating musculature during functional activities. Children were kept motivated with age-appropriate, meaningful functional tasks (including play). Time was allotted for appropriate practice of skills and accurate feedback of results was provided.

Therapists in the intensive NDT program followed the following intervention protocol:

- Therapists will complete a thorough evaluation of each client specifically analyzing effective and ineffective posture and movement behaviors and conducting a systems review of each participant. Systems to be evaluated include: neuromuscular, musculoskeletal, cardiovascular, respiratory, sensory (visual, auditory, tactile, proprioceptive, and vestibular), gastrointestinal, and integumentary.

- Functional goals will be written collaboratively among parents, child (if applicable) and therapists. Goals will be written weekly prior to session interventions and the Goal Attainment Scale format (5 point Likert scale) used.
- Individualized, direct handling will be used with each participant with therapists using their hands on the child with appropriate key points of control (e.g. pelvis, trunk and shoulder girdle, upper and lower extremities).
- Preparatory activities (including somatosensory preparation, addressing appropriate arousal level, and trust /rapport building with parents and child) will be included in the initial 1/3 of the session and continued as needed throughout the session.
- Alignment, base of support, and center of mass (ABCs) will be addressed during each intervention session. Each child will be assisted throughout the session with active alignment and weight shifting the center of mass over the base of support with transitional movements.
- Core muscle activation including flexion with rotation or extension with rotation (or both) will be facilitated as needed.
- Elongation of muscles will occur (if needed) followed by activation activities to maintain elongation.
- Problem solving throughout the intervention session will occur, modifying handling as needed to support functional outcome(s).

- Practice time and repetition of functional outcomes using both simulated and real practice of skills will be completed during each session.
- Team collaboration (therapists, parent and child) will be ongoing and occur during all sessions.

Instrumentation

Qualitative Research

An interview questionnaire consisting of 15 open-ended semi-structured questions was used with the parents for the qualitative component of the research (Appendix A). The interview questions were reviewed and revised with suggestions from a parent interviewed during the original site visit and two therapists involved in the intensive program. The nature of the questions was open-ended and parents were encouraged to discuss their experiences of the intensive program using descriptions and open-flowing communication.

Interview Guide

The parent questionnaire consisted of the following Interview Questions:

1. What has been you, your child's, and your family's experience of having your child participate in this five (or ten) day intensive NDT program? Probe: Describe the process; tell me what brought you to the program and what instructions or information you were given prior to the process. How did you feel about this program initially?

2. How were you and your child's needs met through this NDT program?

3. What were the hopes for you and your child during this intensive NDT program?

4. What needs or hopes for you or your child were unmet with this intensive NDT program?

5. What could have been done to better help you with this whole experience?

6. What has been the hardest part for you and your child about this program?

7. How have you dealt with any difficulties with the program?

8. What has been easiest part for you and your child about the program?

9. How has this intensive program differed from other therapy your child has received? (Probe: be sure to inquire regarding the duration and frequency of therapy)

10. Was there anything that happened specifically (positively or negatively) that you would like to share about the intensive NDT program?

11. Describe your experience with the therapists during this program.

12. If there were three top things you could discuss or pass on to other parents about the intensive NDT program -what would they be?

13. What would you do differently or what would you tell other parents or children to help them with this NDT program?

14. (if applicable-asked only if family participated in the intensive NDT program previously) How was the home program for you and your family?

15. Is there anything else you would like to add?

Interview Protocol

Interviews were conducted after completion of the intensive NDT program with each interview session following the same protocol. The interview protocol consisted of the following: 1. introduction from the researcher and a warm welcome to the participant (try to build trust and rapport at entry stage); 2. before interview begins, review consent, assent (if applicable) and demographic forms to ensure completion of forms and for continued consent for interview; 3. before the interview begins, ask if participant is comfortable and needs anything; 4. ask if the participant is ready to begin the interview, and turn the tape recorder on; 5. if a break is needed for the participant, provide this whenever necessary; 6. ask semi-structured interview questions allowing time for formation of answers and clarifications from participants; 7. take field notes during the interview including an evaluation report of the researcher's own experiences, thoughts, and feelings; 8. at the end of the semi-structured question format, be sure the participant has nothing else to add for the interview; 9. turn the tape recorder off, and thank the parent graciously for participating in the research; and 10. give thank-you gift card to the participant.

Forms (Appendix B, E & G) were used to collect demographic and descriptive data, document intervention and scoring of goals, and record attendance for the participants, their caregivers, and the therapists.

Quantitative Research

Classification of Children Using GMFCS

Children participating in the study were classified using the Gross Motor Function Classification System (GMFCS). Palisano et al.[5] developed the GMFCS for children with CP twelve years of age and younger to assist with stratifying levels of function in children with CP. Five levels of mobility independence exist in the GMFCS ranging from Level I (walking without restriction) to Level V (self-mobility is severely limited).[5] The GMFCS levels are ordinal in nature and based on functional limitations, need for assistive devices, and, to a lesser degree, quality of movement.[5] The GMFCS provides a uniform way for clinicians to classify gross motor function in children with neuromotor disabilities, and to assist with specific comparisons in intervention effectiveness for varying levels of function in children with CP and other neuromotor disorders.

Goal Attainment Scale

The Goal Attainment Scale (GAS) is a criterion-referenced measurement tool commonly used by pediatric therapists.[6] The GAS uses individualized behavior objectives conducive to patient and family participation in goal-setting.[7] It is based on goals scaled for each participant using individualized criterion measures which are excellent for charting progress.[6, 7] A 5 point Likert scale with functional, objective goals set by the child and/or their collaborative team is developed and then used for data analysis. The GAS level of attainment scale ranges from -2 (much less than expected) to +2 (much more than expected). The GAS has many applications in the rehabilitation field due to its ability to assess change during many forms of intervention, and is commonly used to augment standardized measures of classification and outcome.[7] According to Mailloux et al.[8] optimal reliability and validity using the GAS is achieved when 1. goals are accurately identified that are important to the family and client; 2. client's projected outcome is identified; 3. objectives are scaled; and 4. performance is rated following intervention. Goals that are specific, measurable, achievable, realistic/relevant and timed (SMART goals) are recommended.[9, 10] These recommendations for using the GAS in research were all planned and implemented aspects of this study (see Appendix F).

The GAS has gained recognition in the United States and abroad and has been noted to facilitate the process and outcome of planned interventions such as NDT.[7] The GAS can be recommended if "the interest is in measuring the impact or effectiveness of a treatment program or other intervention."[7 (p.5)] For evaluating intervention, the GAS can be used to measure therapy procedure attributes that may not have been captured or measured by existing (quantitative) devices.[7, 11] Recent studies have found parents often place "greater value on those aspects of functioning that are not readily measured by traditional outcome measures"[8(p.255), 12-13] Because this study was novel in its approach exploring NDT using a qualitative research design, the GAS appeared to be an appropriate supplemental evaluation to measure parents' functional goals for their child's participation in the short-term, intensive NDT program.

Canadian Occupational Performance Measure

The Canadian Occupational Performance Measure (COPM) is an individualized outcome measure to identify problem areas, evaluate performance, and satisfaction relative to the problem areas, and detect change in self perception of occupational performance over time. The COPM is administered using a semi-structured interview format using a 10 point Likert scale. The scaling for each of the three scales are as follows: Importance-scores range from 1 (not important at all) to 10 (extremely important); Performance-scores range from 1 (not able to do it) to 10 (able to do it extremely well); and Satisfaction-scores range from 1 (not satisfied at all) to 10 (extremely satisfied). The reliability of the COPM has been found to be well above the acceptable range (>.84), and content, criterion, and construct validity is supported.[14, 15]

Researchers have found the COPM beneficial for facilitating evidence-based practice due to its ease in administration and responsiveness to change and its application during initial assessment and follow-up in a wide variety of clinical settings and different populations.[14, 15] In client-centered practices, the COPM has been found to be responsive to distinct changes in function when clients are receiving interventions beneficial to them.[14, 15] The three possible categories of occupation for exploration on the COPM are self-care, productivity and leisure. Functional mobility is listed under the self-care category. With this dissertation research, the COPM appeared to be an appropriate outcome measure when examining self-care and specifically, functional mobility differences after the intensive NDT intervention program. The COPM had intrinsic flexibility to capture functional difficulties across all developmental levels and throughout the lifespan.[14, 16] The importance of including parents and caretakers in the therapeutic decision-making while working toward improved function of the child is a special clinical application of the COPM. Caregivers can serve as alternate respondents with the interview process; this feature was implemented with the current study.

Data Collection Procedures

Overview

In chronological order, the following events took place during this research:

- consent/assent (if appropriate) forms signed and demographic information taken
- parent interviews scheduled
- in-servicing on GAS and COPM procedures for treating therapists in intensive program followed by weekly interim checks ensuring reliable use of tool (Appendix F)
- collaborative goal setting for children and pre-testing with GAS and COPM
- intensive NDT intervention 2 to 4 hours per day for 5 or 10 days
- post-testing using GAS and COPM weekly after intervention
- scheduled interviews with caregiver after completion of intensive NDT program
- transcription of parent interviews by primary investigator (PI)
- analysis of both qualitative and quantitative data by PI
- research write-up by PI

Figure 3.1 displays the data collection sequence graphed by weekly segments.

The PI conducted all the interviews, collected and analyzed the data on all participants, and prepared the manuscript. The other researchers served as consultants for all phases of the research. This research was approved by the Institutional Review Board (IRB) of Rocky Mountain University of Health Professions (RMUoHP). After IRB approval, the PI recruited participants during the application process for the intensive NDT program. Procedures to ensure confidentiality were employed and informed consent [both parent permission and child assent (when appropriate)] obtained from all participants.

Qualitative Data Collection

Interviews were scheduled via telephone calls, e-mails or face-to-face contact from the PI. A semi-structured interview guide with open-ended questions was used to explore parents' experiences of having their child participate in the intensive NDT program (please refer to previous section for interview guide and protocol). The interviews ranged from 50 to 85 minutes in length. The researcher attempted to keep a calm, comfortable atmosphere for the caregivers interviewed. Caregivers were encouraged to answer all questions with honesty. The investigator attempted to reduce respondent bias by using active listening with encouragement to share all experiences both positive and negative. Qualitative data were collected through a variety of sources (triangulation of the data) including tape recording, field notes, observations, document review, videotapes and photographs. For thorough investigation of both intensive sessions, data collection was continued with all participants in the second intensive program (even if data saturation was achieved in the first session). Each interview was transcribed verbatim. Verification of the data was performed by the PI with 2 of the 15 participants checking for accuracy of the information at the midpoint and end of the interview process. Parents were provided the opportunity to review their individual interview to verify accuracy of the data after transcriptions were completed. Demographic and descriptive data were collected for each participant and child.

Quantitative Data Collection

Quantitative data were collected weekly pre-and post-intervention using the GAS and COPM (Table 3.1 for quantitative research variables and under instrumentation in the previous section). Children participating in the study were classified according to Gross Motor Function Classification System (GMFCS) (Level 1-most independent to Level 5-most dependent). For the therapists conducting the intervention, the PI provided face-to-face training on scoring the GAS and COPM prior to each intensive program's initial data collection (see Appendix F) with an interim reliability check performed after one week of intervention. Individual therapists treating the children during the intensive program collaborated with the family after the initial evaluation of the child to set specific functional outcomes for the child. The outcomes were written using a 5 point Likert scale as specified on the GAS. The GAS was scored on the first day and after each week of intervention. The goals were reviewed by therapists known to the children to ensure they were appropriate and an accurate reflection of the child's functional levels. The COPM was explained to the parent (and the child if appropriate) during the first intervention session and scored on the first day and after each week of intervention. Children received NDT intervention delivered by two or three pediatric physical, occupational or speech therapists consisting of direct therapy for two to four hours during five consecutive days, or for ten days (with one weekend off). Therapy was provided in the same facility at the same time each day for each intensive program; although a different church location was used for the September intensive program. A one hour break was taken half way between each session, daily. Daily attendance of the intervention sessions was recorded for the parent and child participants (Appendices C & D) and the duration of intervention with specific pediatric therapists was documented.

Data Collection Limitations

A convenience sample was used for participants without randomization. Data collection was directly dependent on the number of participants signing up for the intensive programs, their willingness to be interviewed and have data collected on their children during the intensive program. Absence of a control or comparison group was a limiting factor of this study.

Other potential limitations are the possibility that caregivers may not have felt comfortable sharing openly with the PI, and caregivers may have not been able to recall and share all information in one post-intervention interview.

Data Analysis and Presentation

Qualitative Analysis

Research question 1 (qualitative design) was addressed using a phenomenological approach and constant comparative methods. Qualitative data analysis of the caregiver interviews followed Creswell[1, 17] and Moustakas.[18] (Figure 3.2) The steps for analysis of phenomenological research included: describing personal experiences with the phenomenon under study, developing a list of significant statements (horizonalization of the data) with preliminary groupings into meaning units, reduction, and elimination, clustering and grouping significant statements into themes, constructing a textural description of the experience, constructing a structural description of the experience, and constructing a textural-structural description capturing the "essence" of the program experiences of the parents/caregivers using reflective structural analysis.[17, 18] Computer software, NVivo 9, was used to assist with qualitative analysis and management of the data.

All interviews with caregivers were digitally recorded, transcribed verbatim, and checked by review and comparison to the original recording by the PI. Verification of the interviews checking for data accuracy and validity was performed with two caregiver participants: when ½ the interviews were completed, and one at the completion of the interview process. All caregivers were then provided the opportunity to review the completed transcripts for data accuracy and for additional revisions and additions (no revisions were suggested). Interviews were performed using a semi-structured interview guide. The PI structured further questioning to confirm or disconfirm previous evidence for validation of findings. Individual contact summary sheets were maintained concentrating on important quotes and to assist with developing themes. Individual field notes with subjective insight were also documented. Triangulating for corroborating evidence from different sources for theme development was used.

Data analysis for the qualitative component of the research began during data collection and was completed after transcription of all the interviews. All data were reviewed including field notes from interviews, interview data, and associated documents to identify major organizing ideas. Time was taken for reflection to listen and actually hear what was said in each interview taking into account not only the words but the tone and context with which the words were said by the caretakers.

NVivo 9, a software program specifically for managing qualitative projects, was used to assist with the analysis of the qualitative data. The PI reviewed the individual interview transcripts extensively and coded significant statements about caregiver's experience with the intensive program into individual "nodes'. Multiple forms of evidence supported each node. These categories were then reviewed and grouped into "meaning units" or broader themes with evidence supporting multiple perspectives of each category. The completed transcriptions were reviewed examining specific contextual information and compatibility of statements to validate each meaning unit and theme. To establish the reliability of the data process, inter-coder agreement was established with a second independent researcher also coding two of the thirteen interviews validating the meaning units and core themes derived from the primary researcher.

The data were then presented with supporting textural and structural statements from the caregivers. A narrative description of “what” caregivers experienced (textural description) was developed using verbatim examples from the interview transcripts. A description was then written revealing “how” the caregivers experienced the intensive program (structural description). Individual examples were provided for clarity with the textural and structural descriptions. Lastly, a composite description using both textural and structural descriptions of the intensive program phenomenon was written. The “essence” of the whole intensive program experience was revealed.

Personal Reflection

As suggested by Creswell[1, 17] and Moustakas,[18] reflection from the PI describing personal experiences with the phenomenon under study is valuable. This researcher began exploration of intensive therapy programs initially as a clinician, many years prior to doctoral studies. She was not involved personally with the Partners for Progress (PFP) NDT intensive program until her initial site visit July 2009. As a pediatric PT clinician practicing for over twenty five years, inquiries from parents and other clinicians regarding the effectiveness of a variety of traditional and new therapies at varying frequencies were often presented. Examining alternative therapy intensities still producing positive results with clients was an interesting topic. More importantly, investigating intervention for improving function with an increased intensity could provide a viable therapy option for families. Her personal experience of the intensive program began with her association with Linda Kliebhan, the physical therapist co-founder of PFP. The PI was becoming an NDT instructor and during an advanced handling course for this process, both the PFP founder and the PI missed a plane and ended up at dinner discussing the specific intensive program PFP was conducting in Milwaukee. The PI had already decided to perform a qualitative research study on intensive NDT. The PFP intensive program was especially interesting to the PI due to the high caregiver involvement already required by all the participants. After attending the site visit in July 2009, many aspects of the program aligned with the PI's priorities in the study including NDT intervention with expert therapists, collaboration, functional goals, caregiver involvement and education. This PI pursued continuing the study exploring the effects of the intensive program. The PI felt strongly about the importance of providing caregiver's a voice in the therapy choices and care of their children with special needs.

As discussed by Creswell[17(p.159)] it is difficult to entirely set aside a researcher's personal experience with the phenomenon. The Epoch process as described by Moustakas[18] challenges the researcher to set aside prejudgments and promotes neutrality. The PI did consciously try to separate professional biases while interviewing caregivers. The researcher remained open, receptive, and listened intently while the participants described their personal experiences with the intensive program. Although biases do exist, the focus of this research is directed to giving the caregiver participants in the study a forum to discuss their views about the intensive program.

Assumptions

The following assumptions of the PI were identified:

- Parents and caregivers of individuals with disabilities have unique circumstances as compared to parents/caregivers of typically developing individuals.
- Many individual and contextual factors influence perceptions of parents and the care of children with disabilities.
- Therapy is an important entity for families of children with disabilities.
- A variety of intervention options exist but may not be available to all families of children with disabilities.
- Frequency, intensity and duration of intervention for children with disabilities vary.
- The amount of collaboration between individuals treating children with disabilities may differ.

- The availability of therapy can vary in different programs and states.
- Appropriate therapy is just one of the many needs for children with disabilities.
- Therapists and parents try to do the best they can with children with disabilities.

Standards of Validation and Evaluation

As recommended by Creswell,[1] strategies for internal validity were employed including triangulation of the data, verification from the participants during the analysis process, repeated observations, and research verification from an independent researcher. To strengthen credibility, all completed transcriptions were sent to participants for any modifications and to confirm accurate representation. Two interviews randomly selected from the 13 interviews transcribed were independently reviewed by an expert qualitative researcher confirming category construction improving reliability and agreement of theme development. To ensure external validity, the primary strategy was the researcher providing rich, detailed descriptions for future comparisons. An experienced qualitative researcher served as the advisor for all qualitative phases of the research.

Quantitative Analysis

To address Research question 2 (quantitative design), statistical analysis using the SPSS 15.0 data processing program was performed on GAS and COPM data collected weekly from each participant. Analysis of demographic information (descriptive statistics) was performed using nonparametric measures establishing mean and standard deviations of each participant. For comparing weekly GAS pre-and post-intervention scores, scaled scores were converted to t-scores. The Wilcoxon signed-ranks, paired t-test was used to determine the mean difference between pre-test and post-test GAS scores each week among the individuals receiving the intensive NDT program. For comparing the weekly COPM pre- and post-intervention scores, the Wilcoxon signed-ranks, paired t-test was used to determine the mean difference between the pre-and post- COPM scores each week among the individuals who received the intensive NDT program. The COPM scores were based on a 10 point Likert scale/ordinal data requiring non-parametric statistical analysis. Although the GAS scores are on a continuous (ratio) scale, nonparametric statistics were used due to the small sample size and the unmet assumptions of normality and homogeneity of variance required for parametric statistics. For all quantitative measures, a statistical significance of $p<.05$ was set *a priori* and power of .80 was used. A 95% confidence interval level was used when analyzing mean scores and effect size from the data.

Institutional Review Board

A review of human subjects from Rocky Mountain University of Health Professions Institutional Review Board (IRB) was required to protect the rights and welfare of human subjects participating in the study. Children with disabilities involved in this research were considered a vulnerable population, and a full IRB committee review was required. Subjects were recruited through the handling intensive program application process. Separate forms with RMUoHP approval for consent to participate as a research participant (for parents/caretakers of children with disabilities), parental permission/informed consent forms, and assent to participate form (for minors) are included in Appendix I. Approval from the IRB was obtained July 1, 2010 with data collection concluding October 2010. An application for a continuation for data analysis was submitted with approval from the IRB March 2011.

Summary

Research methods for this mixed method study were reviewed in this chapter. Instrumentation was described including the qualitative interview guide, protocols, and quantitative outcome measures, the GAS and COPM. An overview was provided of data collection procedures with study limitations. Data analysis methods and personal reflection and assumptions were described. Procedures for full IRB approval were explained.

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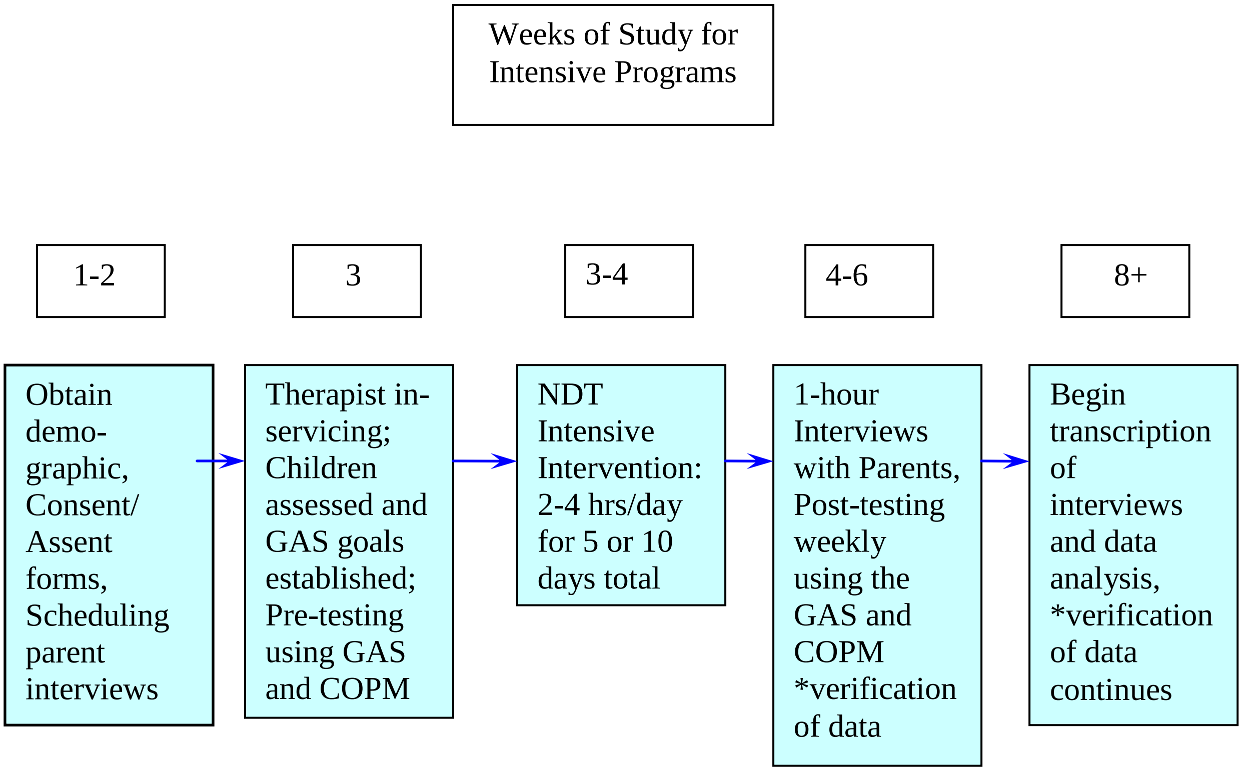

Figure 3.1: Data Collection Flow Chart of Study Design (showing timing of assessments and intervention)

*verification of the data with 2 parent participants; a. mid-study; when ½ of the interviews were completed; and b. at completion of the interview process. Parents were provided the opportunity to review the completed transcripts for additional revisions and additions.

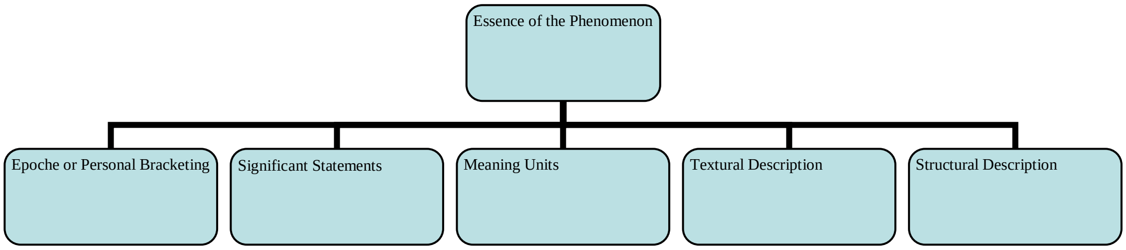

Figure 3.2: Qualitative Data Analysis (Phenomenological approach per Creswell[15])

Table 3.1: Quantitative Data Analysis

Dependent Variable	How measured? (scale)	Independent Variable	How measured?	Examine	Statistical test
GAS	Ordinal (5 point Likert scale converted to t-scores)	Children will be classified in severity using GMFCS-Level I-V	Interval -2,-1,0,+1,+2	Means	Wilcoxon signed-ranks, paired t-test
COPM	Ordinal (10 point Likert scale)	Children will be classified in severity using GMFCS-Level I-V	Ordinal 1-10	Means	Wilcoxon signed-ranks, paired t-test

CHAPTER IV

Results and Presentation of Qualitative Data

Demographic Findings

Description of Parent Participants for Interviews (Qualitative Data)

Caregiver interviews were conducted during two 2010 intensive program sessions: summer and fall. Nine interviews were conducted in the summer session, and four interviews occurred in the fall session. Twelve of the thirteen caregivers interviewed were the child's Mother and one was the Grandmother. All caregivers spoke English, and no translation was required. All interviews ranged from 50-85 minutes in length.

Description of Children Participants (Quantitative Data for GAS and COPM)

A total of sixteen children (11 males; 5 females) participated in the two intensive programs. The mean age of participants was 7 years, 5 months (range 1-17 years). The majority of children (13) functioned at the GMFCS Level III-V (more severely involved), and three children functioned at the GMFCS Levels I or II (Table 4.1, 4.2, 4.3 & Fig.4.1).

For the first intensive session, a total of 9 children participated in the intensive program. Parents were provided the choice of having their child participate in either one or both weeks of the summer session. Three children participated for half days only. Two of these children participated in the two week session (and were two years old); and one child participated for only one week, but for the full day.

For the second intensive session, a total of 7 children participated in the intensive program. This session was provided in the fall, and the session was only a week in duration; a two week duration was not offered (due to children still being in school). Two of the children participated in half day sessions only (one of these children was age two).

Three children participated in both the summer and fall intensive programs. Individualized goals were written for each week of the intensive program. If a child participated for two weeks during the first session, goals were scored after the first week and revised if needed for the second week. If the child participated in both the summer and fall intensive sessions, goals were different for the fall session. Using the GAS, goals were collaboratively written with the caregivers and new therapists treating the children for the fall sessions.

Quantitative Results

A total of 16 participants received NDT intensive intervention. The distribution of severity of each of the participants is represented in Figure 4.1. Three participants were involved in both intensive sessions. Of the 16 participants, 16 of the children completed at least 70% of the intervention sessions, attended both pre- and post-test sessions of the GAS, and were included in the statistical analysis of the GAS. One participant completed 70% of the intervention sessions, attended the pre-testing of the COPM, but was not present on the last day for post-testing of the COPM, so was not included in the statistical analysis for the COPM. There was no attrition of subjects affecting the study.

The NDT intensive weekly GAS intervention mean scores were significantly different following intervention ($p<.001$) from pre-test mean scores. The hypothesis that a difference would occur in GAS scores after intensive NDT intervention was supported (Tables 4.4, 4.5, 4.7 and Figure 4.2)

The NDT intensive weekly COPM intervention mean scores were significantly different following intervention ($p<.001$) from pre-test mean scores. The hypothesis that a difference would be found in COPM scores after intensive NDT intervention was supported (Tables 4.4, 4.6, 4.7 and Figure 4.3). Per Law and colleagues[1], change in two or more points on the COPM indicates a minimal clinically important difference (MCID). The NDT intensive weekly COPM performance and satisfaction post-intervention scores had more than a 2 point difference compared to pre-intervention scores indicating a MCID (Table 4.6 & Figure 4.3).

A site visit to Milwaukee, Wisconsin was performed July 2009 with the researcher participating in the NDT intensive program, using the GAS and COPM for pre- and post-testing after intervention with one child (case study), and interviewing the parent to sample the interview questions. Suggestions were solicited from the parent and incorporated into the proposed research interview questions. The GAS and COPM were scored for the child with improvements noted in both scales (Table 4.8). This site visit data was not included in the final quantitative data results of the study (no IRB approval was solicited for the site visit or needed to conduct the single case report).

Subjective Results from Therapists on Quantitative Instrumentation

Pediatric therapists were asked regarding their experience using the quantitative outcome measures, the GAS and COPM, with children during the NDT intensive program. The following comments were obtained from the therapists using the instruments:

"I liked them. They were not difficult to use at all."

"It was very easy. It was what we already do anyway (with goal writing).

"It was nice to work with peers" (for collaborative goal writing)

"It was fine-we could have written goals and the children made changes not reflected in the goals- but I still liked them."

"Very easy to use and good instruments to assist with being accountable in goal writing."

Presentation of the Data-Qualitative Results

Individual Descriptions of Families

Individual descriptions of each of the families participating in the intensive program are provided to assist with contextual information provided in the interviews of the caregivers (please refer to Tables 4.1, 4.2 and 4.3 for further child and caregiver demographic information). The names of the children have been changed to protect their identities.

AO1: “Allie”

The first caregiver participant interviewed was Allie’s mother. Allie was a two year old girl with the diagnosis of a chromosome abnormality. She participated in both the summer and fall intensive sessions. Allie attended for half days only for the first week of the summer session, and half days only for the week of the fall session. The summer session was the first time Allie had participated in the intensive program. Therapy services Allie received consisted of Early intervention (EI) services with PT 2x/week, OT 1x/week and SLP 2x/week.

Allie’s Mom was interviewed in one of the smaller rooms used for the therapy intervention at the church. She was very relaxed and had excellent eye contact. She expressed positive comments about the expertise of the therapists working with Allie, and all working together as a “team” to best help Allie. She appreciated being listened to and enjoyed the open communication of all working with Allie. She mentioned initial uncertainty of the intensive program’s effects with Allie and later feeling “illuminated” by seeing and understanding the important building blocks achieved for Allie’s improved function. She reported all should try the intensive program and make it a priority.

AO2: “Bella”

The second adult participant to be interviewed was Bella’s Mom. Bella was a six year old girl with the diagnosis of cerebral palsy (CP) (GMFCS Level IV). She lived at home with her parents and two older siblings aged 7 and 8. Bella participated full days in the first week of the summer session. It was her first experience with the intensive program. Regular therapy services consisted of both school-based and private therapy services. At school PT and OT 1-2x/week were provided. Private therapy services consisted of PT and OT 1x/week for one hour sessions. During the intensive program, Bella and her mom were staying with her sister because they lived two hours away.

Bella's Mom was interviewed in a large open room used as the church's cafeteria. She used a very quiet voice but seemed relaxed during the interview. She smiled often and talked comfortably. She shared positive comments about the intensive program. She thought the working therapists brought many years of knowledge and demonstrated a "genuine concern" for her daughter. She enjoyed the environment; it "felt like home" with a laid-back atmosphere, and having lunch provided was appreciated. She mentioned liking the collaboration and the overlapping intervention times of the PT and OT sessions. New ideas with equipment and having "new eyes" of the therapists to assist with Bella were helpful. She mentioned that the home program provided was helpful, and the intensity of the intervention sessions assisted with practicing the goals.

AO3: "Chad"

Chad's grandmother was the third adult caregiver to be interviewed. Chad was a five and a half year old boy with the dual diagnoses of cerebral palsy secondary to a stroke and a chromosomal abnormality. He lived with his grandparents and little sister. Chad participated for the first time in the intensive program by attending the first week for full days in the summer session. He was receiving school-based therapy services consisting of PT, OT and SLP 5x/week. Chad had other psychological issues also being managed in private therapy.

Chad's grandmother was interviewed in one of the therapy rooms with the door closed. Initially, she seemed a little uncomfortable keeping her arms crossed in front of her. By the second or third question, she was much more relaxed with her arms down and easily maintaining eye contact. She expressed discontent with the medical profession and the health care system including funding for therapies. She would have liked to have had more information about what to expect with the intensive therapy sessions. She expressed never even witnessing "therapy" so everything was new to her and a bit overwhelming. She shared she did like the team work, the collaboration between the therapists, and the therapists' professionalism. She was pleased with the new ideas to help Chad. She especially thought the peer interaction was beneficial for Chad.

AO4: "Danielle"

Danielle's Mom was the fourth caregiver to be interviewed. Danielle was an almost two year old child with the diagnosis of developmental delay and neonatal seizures. She had one older brother and lived at home with her sibling, and Mother and Father. Danielle attended half days for the two week intensive summer session, and full days for the one week intensive fall session. She had not attended an intensive program before the summer experience. She was receiving EI services consisting of 3x/week PT, and 2x/week of OT and SLP. She occasionally received supplemental private therapy services.

The interview with Danielle's Mom took place in a large treatment room. She seemed comfortable and maintained good eye contact during the interview, although often talking quickly. She expressed being very pleased with the intensive program stating it was "wonderful." Danielle's mom liked "a new set of eyes" and the fresh perspective the treating therapists brought to Danielle's sessions. She mentioned appreciating "a positive" vs. negative voice from the therapists as she had experienced in the past. In addition, she shared being a little stressed initially in the intensive sessions wanting Danielle to do well and also making sure she was okay. She identified this stress on her own and felt after trust was established with the therapists, her stress decreased significantly. Danielle's Mom did express disappointment with not really being able to connect with another family with a child similar to Danielle. She related that talking to other parents with children with special needs assists in changing parent's perspectives of their own child (especially if a parent has a child with more severe problems).

AO5: "Evan"

The fifth caregiver interview was with Evan's Mom. Evan was a sixteen year old boy with the diagnosis of CP (GMFCS Level III). He had many surgeries that were "too numerous to name." Evan lived at home with one younger sibling and both parents. Evan attended the second week of the summer session for full days. He had participated in the one week intensive sessions previously. Evan received school-based services of PT 2x/week and Speech Therapy 2-3x/week. Private OT services were received 1x/week.

The interview with Evan's Mom took place in Evan's treatment room. She seemed very relaxed, talkative and had excellent eye contact; it was the longest interview. She discussed positives of the intensive program including receiving different ideas from many therapists and liking having equipment to try before purchasing expensive items. She discussed the benefits of co-treatment as her son was getting bigger, and was frustrated by insurance not covering it. She expressed appreciation for the home program provided with the intensive programs, and felt it was helpful to her in assisting with her son at home. Discussing the intensive programs in general, she stated: “He accomplishes more in this week than he does in a month of regular therapy.”

AO6: “Fernando”

The interview with Fernando’s Mom was the sixth caregiver interview to be performed. Fernando was a seventeen year old boy with the diagnosis of CP (GMFCS Level V). He lived at home with one younger sibling and his parents. He received private therapy services of 2x/week PT and OT, and 1x/week Speech Therapy. Fernando attended the summer intensive program for the two week duration, for half days. He had attended the weekly intensive programs previously.

Fernando’s Mom was interviewed in her car while waiting for her younger son to finish baseball practice. The interview had been planned earlier, but Fernando’s intensive session had run over the time for the scheduled interview. Fernando’s Mom was relaxed and seemed comfortable even with the last minute change of where the interview took place. She reported positive results from the intensive sessions which were why she continued to participate in them. For Fernando, she felt the intensive sessions were the best therapy to meet his needs as he grew older. She expressed the home program provided with the intensive program to be helpful for sharing with others in the family and at school helping to assist with Fernando. She expressed having NDT therapy, specifically, for Fernando was important to her. She sought NDT trained therapists throughout the years to treat Fernando. She expressed the intensive program as being “intensive” but “so worth it.”

AO7: “Grayson”

Grayson’s Mom was the seventh caregiver interviewed. Grayson was an almost three year old boy with the diagnosis of mild CP. He had a typically developing twin, and an older brother. He lived at home with his parents and two siblings. He was still receiving EI services with PT and OT 1x/week and Speech Therapy 2x/month. He also received supplemental private PT 1x/week. He participated in the second week of the summer session for full days and had not attended the intensive program previously.

Grayson's Mom was interviewed in the hallway; there was one short interruption when ladies were talking loudly but this was of a short duration. She seemed comfortable and sat back in her chair during the interview. She reported positive aspects of the intensive program and was surprised how well her son had done because he was one of the younger children participating in the program for full days. One of the best benefits of the program for her was the social connection with another mom and child close to her son's age with similar special needs. She expressed disappointment in her son not receiving more speech during the intensive program; but was pleased overall with the program. She did express difficult times having a child with special needs and from hearing hurtful words from the medical profession. She had been told from her pediatrician her son "was lazy" and he was not diagnosed with CP until recently (when he was 18 months of age). She reported the foundation skills and repetition for Grayson in the intensive sessions were important.

AO8: "Holden"

The eighth caregiver interview was with Holden's Mom. Holden was a three and a half year old boy with the diagnosis of CP. Holden lived at home with his two younger siblings and parents. Holden attended the second week of the summer session for full days. He had not participated in the weekly intensive sessions previously. Holden received private therapy services in the summer consisting of PT 2x/week (one of these sessions consisting of PT for 30 minutes, and hippotherapy for 30 minutes), OT 1x/week and Speech 1x/week.

Holden’s Mom was interviewed at a table in the hall. It was very quiet in the hallway during the interview. She seemed comfortable and very relaxed while talking during the interview. She expressed the intensive program had been “wonderful” and she loved that the pediatric therapists for the intensive program were from all over the country. She liked the home program to assist with sharing information with Holden’s Dad and other therapists. She did express discontent with insurance coverage for Holden’s therapy needs.

AO9: “Isaac”

Isaac’s Mom was the ninth caregiver to be interviewed, and the last interview from the summer session. Isaac was six and a half years old and had the diagnosis of CP (GMFCS Level IV). He lived at home with his parents, older brother and sister. Isaac attended both weekly sessions in the summer for full days. He missed one full day out of the two sessions due to traveling for a family event. He had participated in the prior intensive sessions, but never for two full weeks. His regular therapy consisted of school-based services: PT, OT and Speech 2x/week.

Isaac’s Mom’s interview was initiated in the hallway and then later moved into a treatment room due to someone needing access to the computer in proximity. She seemed very calm and comfortable with good eye contact during the interview. She seemed to be carefully thinking about the words she used to answer the questions. The main feedback was very positive regarding the intensive programs. She shared her appreciation of the therapists of varying disciplines working collaboratively to “look at the big picture” for her son. She expressed liking the goal setting process for Isaac focusing on his target areas for the intensive program. She reported returning to the intensives even though they were “exhausting-but so worth it”, and she would recommend it to anyone.

A010: "James"

The tenth caregiver and first interview of the second intensive session was with James' Mom. James was a twelve year old boy with the diagnosis of CP (GMFCS Level V). He lived with his Mom and did not have siblings. He participated in the full day program of the fall intensive session. James missed 2 hours on the last afternoon session due to a family emergency (COPM was not scored). His regular therapy consisted of school-based services: PT/OT/Speech for 30 minutes 1x/week, and outpatient OT 1x/week and PT 2x/month.

James' Mom was interviewed initially in the therapy room and then moved to a smaller room to finish the interview. She was very agreeable to being moved and seemed to be at ease and comfortable during the interview. The smaller room was a little louder but both the interviewer and the Mother could be heard. She reported the intensive program was a very positive experience for her and James. She voiced discontent with James' current school therapy and with insurance coverage for necessary therapy. She liked the therapy collaboration at the intensive program. She shared it was a positive and different experience for her to have therapists that "listen to the parents and the child". She felt this was an important positive aspect of the program.

AO11: "Kevin"

Kevin's Mom was the second interview of the fall intensive session and the eleventh caregiver to be interviewed. Kevin was fifteen and a half years old and had the diagnoses of CP (GMFCS Level V) and cortical blindness. Kevin lived at home with his parents and did not have any siblings. He received school-based services: PT/OT and Speech Therapy 1x/week and also received private therapy services: PT 2x/week and OT 1x/week.

Kevin’s Mom was interviewed in a large therapy room. She seemed calm and relaxed, maintaining good eye contact and talking freely. She expressed very positive perceptions of the intensive program. She was pleased specifically with being able to see what Kevin could still accomplish at his age. She expressed the importance of using an intensive program to “jump start” Kevin’s skills. She liked the collaboration of the therapists and expressed the importance of therapists establishing a rapport of trust with their clients.

AO12: “Liam”

The twelfth caregiver and third interview of the second intensive session was with Liam’s Mom. Liam was a four year old boy with the diagnosis of CP (GMFCS Level II) and profound hearing loss with cochlear implants. He was an only child living at home with his parents. Liam attended full days for the week intensive session in the fall. It was the family’s first experience with the intensive program. His regular therapy was school-based with PT and OT provided at a frequency of 2x/week, and Speech 4x/week. He also received supplemental OT and Speech Therapy at a private clinic 1x/week.

Liam’s Mom was interviewed in the therapy room. She seemed very relaxed, comfortable and had good eye contact. She shared the intensive program was very positive but also very “intensive”. She voiced positive perceptions of the staff and individual therapists saying they were “awesome” and “incredible”. She discussed the desire for more parent mentoring and frustration with insurance not covering needed therapies. She also shared experiences with questions from others regarding having a child with disabilities, and how she dealt with that personally.

AO13: “Mitch”

The last interview to be conducted was with Mitch’s Mom. Mitch was a two and a half year old boy diagnosed with a chromosome abnormality. He lived at home with his parents and did not have siblings. He participated full days in the fall session of the week intensive program. His regular therapy consisted of private therapy services: PT 1x/week, OT 2x/week and Speech Therapy 2x/week.

Mitch's Mom was interviewed in the large classroom being used for therapy. She maintained good eye contact and was relaxed throughout the interview. She expressed "really liking" the intensive program; it provided the intensity of therapy and repetition that she felt helped Mitch the best. It was "hard work" for him but "so worth the money". She reported having a negative experience with the EI program and needing "more aggressive" therapy for her son. She also expressed appreciating the collaboration between all the therapists in the intensive program.

First Research Question (qualitative design): "What has having your child participate in this intensive NDT program been like for your family and you as parents of a child with a disability?

Clustering of Meanings/Invariant Constituents into Core Themes

The researcher analyzed each of the verbatim transcripts, field notes and observations of the 13 caregiver interview participants. From each transcript, significant statements or sentences pertaining directly to the lived experience of participating in the NDT intensive program were identified. A total of 26 descriptions or meaning units called "invariant constituents" as labeled by Moustakas[2] were revealed. These invariant constituents conveyed multiple perspectives from the participants and assisted to interpret the meaning from the descriptors of the caregivers of the intensive program. The invariant constituents were then developed into "clusters of meaning" from the significant statements through reflection of the interview transcriptions into themes.[3] Seven themes emerged and themes were categorized into caregiver effects, child effects, and combined caregiver/child effects. Please refer to Tables 4.9 and 4.10 for further information on invariant constituents and theme development.

Themes

Theme 1. Effects of increased intensity of intervention were viewed as highly beneficial by caregivers.

The feelings regarding the intensive program of all thirteen of the caregivers interviewed were very positive. Several caregivers felt the intensive met their child's needs and their own expectations very quickly. Many caregivers expressed strong feelings of seeing success in their children with the intensive program and compared the intensive to the more traditional therapy their child was receiving. A few of the caregivers had participated in an intensive program previously and were happy to be participating again. Other caregivers were pleased with the new experience. Many caregivers expressed the feelings of hope and excitement with expectations exceeded from seeing improvements in their child with the intensive program.

Caregiver Effects

Statements from caregivers illustrating positive effects and important benefits of the intensive program:

"I just think it is a wonderful experience. A positive experience and I would recommend it to anyone." (caregiver of Isaac)

"I got here- it has been wonderful. We've noticed improvements- my husband notices it when he comes home." (caregiver of Holden)

"My husband and I and my mother who has come too to some of the therapy sessions-we see what this has done for her. And we're very passionate about it and very supportive of it. I think people hear us talk about it and even though they don't know what exactly is going on here- they know that it's a good thing for her." (caregiver of Allie)

"He responds-I don't know if other- you know when I talk to other parents-I don't know if their child would respond- but (my son) just makes leaps and bounds with this kind of therapy." (caregiver of Evan)

Caregivers expressed specific intensive program benefits compared to more traditional therapy

"I think it gives them a push. I think he gets successful and the feeling that he can do it more- and then overall-he accomplishes more in this week then he might accomplish- in like- a month of regular therapy." (caregiver of Evan)

"You have carry over -and that's when you get to see more intense progress-because- you don't lose anything in between the weeks."(caregiver of Isaac)

"Because I'm thinking maybe if we did the intensive- then we wouldn't necessarily need to see the PT, OT every week- if we could keep it going."… "I think (regular therapy) it is very monotonous. We do this every week and - the intensives-I mean-he's just getting so much out of it." (caregiver of Liam)

"Intensive- that's what he needs. He needs more aggressive kind of therapy and I'm all for that. I wanted something more aggressive…because it's repetition for my son-so the more repetition you can get-like in a week's span or longer- would be nice but- I think better... Rather than an hour a day." (caregiver of Mitch)

"Because with the consistency being the intensive- that makes the difference. (the intensive program) gives him confidence." (caregiver of Fernando)

"I like that it is an extended period of time. So often-you're- when you're in therapy- any kind of therapy at any age- you have kind of a "warm up" period and by the time you really get into it… your session's done and I think here because you have a little bit more time, and you're here five days straight- you have the opportunity to just continue to-to carry it over and there isn't that gap." (caregiver of Allie)

"The intense I like because it's like consistent. It's longer- hard core. More than an hour which is the normal therapy he gets." (caregiver of Holden)

Combined Effects

Statements from caregivers illustrating positive effects and benefits of the intensive program for both caregiver and child

"Coming back in October wasn't even a question … it was a given. We did the intensive in October of last year and it was fantastic. Before the end of the therapy she was sitting up on her own which was one of our biggest goals." (caregiver of Allie)

“When we lived in (different state) to do intensive therapy with (my son) and that’s when we noticed that he does really well doing that. Because sometimes when you just have once a week PT or whatever- he wasn’t-He was showing such gains in that whole week or even in a three, four hour session for a couple days in a row then he would actually show in like-one hour- of whatever. It seemed like his tone and all the things- it just seemed to stay longer with him- so that’s why we continued to do it.” (caregiver of Evan)

“I mean seriously-like if I could somehow come up with a sponsor for me to set up a foundation- for something like this for kids like (my son) and this kind of intense therapy- because not only is he sitting there drawing pictures-and you know- things that are little to us- that are huge for (our son). I mean- wow I’d love this kind of a program all year around.” (caregiver of Grayson)

Statements from caregivers suggesting intensive program improved sleep of child

“What I’m seeing is it (relaxation) continues after the sessions. To know-he’s home, he’s asleep and in for the night. Usually- seven weeks after botox-(my son) does not sleep through the night- he falls asleep, he wakes up and he doesn’t go back to sleep. He sleeps around four to five hours at that time. And this week-he’s sleeping what he usually sleeps- nine to ten hours.” (caregiver of Fernando)

“When we get home- he still has all this energy and he goes to bed earlier- but he sleeps good…Because it’s just like-as the week went on- he lasted longer and longer throughout the day. So I think as his sleep got better...he lasted longer and longer.” (caregiver of Mitch)

“She’s been taking (after intensive) - getting a good nap in the afternoon.” (caregiver of Danielle)

Combined Effects

Provided hope for caregivers with exceeded expectations

“You know-we really wanted to have him beef up the skills he learning. So it’s really- I mean- I think they (our goals for the intensive) met it the first day- honestly…I don’t know what I expected- but he’s definitely exceeding my expectations.” (caregiver of Liam)

“They give with this intensive- with the amount of hours and the intensity of it- it does give you that glimpse. And I saw that yesterday. Now if you can sit there and imagine- you’re being seen four to five hours a day and it took the third day- and you’re looking at like- what-three months, four months worth of regular therapy- if you’re going once a week? That then you won’t see that until then. Whereas with this case-with this program- I saw it on the third day…He still has a lot- he can still do more- he can still accomplish more. I just need to pick up his therapy- and aggressively… My expectations just in the third day- were already met. A hundred percent guaranteed-satisfaction is what I got!” (caregiver of Kevin)

"It just sort of- opened my eyes. I mean- I don't even have the words to explain it. It just was very motivating and emotional for me to see the kids that are here."(caregiver of Liam)

"I think what it is doing- is making (my son)- feel what he's supposed to feel like. Whether he can grasp it at this age- but I'm – more importantly- it's just for (my son) to actually feel it…like feel the muscles relax."(caregiver of Grayson)

Theme 2. Unique qualities of the therapists such as expertise, being a good teacher, having compassion, good listening skills and providing hope were essential keys to the success of the intensive program for caregivers.

Specific traits of the therapists providing intervention at the intensive program were noted by caregivers as important to the success of the program. All thirteen caregivers interviewed reported positive personal qualities of the therapists treating their children including demonstrating expertise and professionalism, being passionate and flexible, showing kindness, and bonding/working well with the individual child. The knowledge and years of experience of many of the therapists was seen as a positive aspect. Many caregivers specifically mentioned the importance of the therapists having expertise with NDT training. Along with having expertise, caregivers felt teaching and being able to educate and explain techniques thoroughly were key aspects of the intensive program. Knowledge was empowering and provided hope for caregivers. Celebrating successes and having a positive attitude were two attributes also expressed and noted by the caregivers.

The data also revealed the caregivers expressed the importance of a receiving a fresh perspective from the therapists in the intensive program. The caregivers expressed two highly appreciated qualities observed in the therapists treating the children: genuine listening and mutual respect. This respect was not only expressed between the therapists and the caregivers, but also with the therapists in their treatment with the children. Being able to read the children's cues and having respect for their input including patience and waiting for responses was greatly valued by the caregivers. The importance of having a comfortable environment with caring individuals for learning was appreciated.

Combined Effects

Therapists seen as experts with professionalism in the pediatric field

“All of the therapists- just bring their experience and education.” (caregiver of Allie)

(The) “Expertise of the professional disciplinarians and we’re coming out with a lot of resources and exact- to the point-suggestions to not only maintain but to enhance his skills.” (caregiver of Chad)

“I think they both have a lot of experience and they come here with- (they) bring all that knowledge with them.” (caregiver of Bella)

“Having so many therapists here and therapists that have been- I don’t know how I want to say this, you know, been doing this a lot of them for quite a long time. And so they come with a lot of things. Of–this worked, this didn’t work.”(caregiver of Evan)

Specifically, NDT training of the therapists was highly valued by many caregivers.

“They’re all NDT trained and they know very well what they are doing.” (caregiver of Fernando)

“He just seemed to respond very well to this type of therapy (NDT) so that’s why we’re here.” (caregiver of Evan)

“I think I’ve learned some things about the components from the physical therapy side here- the NDT I’m seeing.” (caregiver of Danielle)

A few caregivers shared only having NDT-trained therapists treat their children

(In another country) “He was in Bobath-everyone was trained. And (my son) was (had) severe involvement. And then we had the Bobath instructors see him-for two years. And then I said- I don’t know what this Bobath means- what is this? Maybe he needs some other techniques. I start thinking that after reading a lot… I looked for other options- and I came back to Bobath. Because that is (what) works best for my son…He was four and a half when he moved to U.S. And here- right away- I asked for NDT…I always ask-all the therapists that he has- I ask for therapists that have NDT training- and that’s what you have in this intensive.” (caregiver of Fernando)

“The therapists (my son) have…go to an NDT course.” (caregiver of James)

Child Effects

"It's a different experience for us because it's like holding a normal (boy)-you know-a child-like with muscles that work. I think what it is doing- is making (my son)- feel what he's supposed to feel like." (caregiver of Grayson)

"I think the hardest part for him is that he's totally –his body feels totally different." (caregiver of Liam)

(with NDT intensive program) "He got a lot more mobile- mobility, and he got his muscles stretched out, his shoulders-came back. Just everything that the doctor said that needs to be done in therapy- I've seen a whole lot of progress this week. His rib cage came down-just- he sleeps better- his breathing is a lot better-getting more sounds, his vision has improved." (caregiver of Mitch)

Caregiver Effects

The sharing of knowledge and verification of information is empowering to caregivers providing hope and motivation simultaneously

"So the teaching part of it- or the education part of it was helpful… to help the parent to understand to carry it over at home." (caregiver of Isaac)

"I think that education part for me was really important…We'd like to get the goal of crawling and that was one of the hopes that she would be potentially be crawling by now…And on one hand it's like- oh we should be doing more things-or we should be trying different things- but I understand because of the explanation and that is such a major component that's it's almost more important to have this down." (caregiver of Danielle)

"One of the things that I think is helpful for me as a parent is to-sit down and specifically come up with ways within our daily schedule to implement the recommendations. (The OT) sat down with me this morning and we were able to do with (my son's) one hour morning routine- to talk about ok- it'd be best for him to be in the stander-and then to work on some proprioceptive- hand pounding-and just really specific guidelines and on a schedule so that we can take those things and apply them." (caregiver of Isaac)

"I learned a lot about now what needs to-in order for walking to happen- I need to know- I learned how the body works- that he needs to control his upper body most to control his walking- so now I know- that in time it will happen- it's just going to take a little more time. " (caregiver of Mitch)

"This kind of program- it's great – because we are learning what we need to do for (our son)." (caregiver for Grayson)

"I felt like I needed that input from somebody on the outside to tell me what could work for him- and what would work- what would make my life easier to handle him. And I did get that out of this program. I did get all of that feedback. I felt like-ok – I know what needs to be done now to jump start him back up. To maybe get some more responses from him- to maybe get some more functional stuff out of him-and that's what I was looking for." (caregiver of Kevin)

Combined Effects

Unique personal qualities of the therapists participating in the NDT intensive program contributed to the success of the program

The therapists were passionate about what they do

"Again it comes back to the fact that everybody that is involved with this program is just as passionate as we are about seeing these kids succeed in everything they can. So it is nice to know that they're not here because it's their 9 to 5 job, this is what they do to put food on the table… they're doing this because they're passionate about it and I think that the kids and the parents pick up on that. You know-That they enjoy what they're doing." (caregiver of Allie)

"They (the therapists) were very professional, they were very versatile, flexible, they were caring and sympathetic to his needs. They were thorough. They were friendly and helpful and I think generally concerned about children with disabilities- wanting to make a difference." (caregiver of Chad)

"They are really special people." (caregiver of Fernando)

"They (the therapists) were completely awesome…I think this staff is incredible." (caregiver of Liam)

"I have to say- the therapists were wonderful. You can just see their desire to help-you know- to bring it all together and to help the parents to understand it. It's been really good." (caregiver of Isaac)

Child Effects

The therapists were connected with the children to gain their trust--displaying qualities of patience, listening and reading cues well

"I felt like everyone was really gentle in terms of their approach, and getting to know her, and then even now. The way they engage her in play-has been gentle-no one's been kind of rough. Or no one is pushing her around too hard. It is yielding to what she can do- but yet-waiting her out- having the patience. I mean the physical therapist is waiting for her to do what she should do." (caregiver of Danielle)

“They listen to (my son) so when (my son’s) had enough – he pushes back-so they’re following (my son)…They were listening to his body and I know that- that they won’t push him too much.” (caregiver of James)

“I think (the therapist) is amazing. He (my son) connected with the therapists.” (caregiver of Grayson)

“They knew when they were pushing his limit. They quickly made it fun.” (caregiver of Holden)

“They read (my son). They are learning him and so quickly… I couldn’t ask for more.” (caregiver of Fernando)

Combined Effects

The therapists demonstrated positive attitudes and celebrated successes instilling hope and higher expectations for the children and their caregivers.

“I think one of the positives things was like when he did something- that just- you know- surprised us all-we all kind of cried.” (caregiver of Mitch)

“I mean-she does something good and it’s a big celebration. And the negative stuff- it’s not ignored, but not emphasized I guess-but the positive stuff- even the small accomplishments are rewarded and praised and I appreciate that….I love how positive they are about everything.” (caregiver of Allie)

“The therapists-they’ve been very positive. They’ve- they have that genuine-wanting to make things be successful for her…They’ve just been very positive about pointing out her success- what she’s doing right.” (caregiver of Bella)

“That’s a big thing that positivity-that they (the therapists) have.” (caregiver of Evan)

“To me it’s nice to get that kind of positive voice- because you know, sometimes we don’t always get that kind of positive message from physicians or people that see her…we know that there’s a risk- but I’ve realized from that- it changes a parent’s perspective to be told a negative thing… and then the parent’s lower their expectations.” (caregiver of Danielle)

Combined Effects

The value of the therapists taking time to listen and gain trust, meeting the child based on developmental status, and treating the entire family with respect is very important for an effective therapist/client/caregiver relationship

“Therapists listened to what I thought were the problems and what I really wanted to work on… They included me.” (caregiver of Holden)

“You guys are nice and you know- you listen to the parents- you guys listen to the child-so that’s the most important part- listening to the children and their body- and how much they can take- and how much can you push each child.” (caregiver of James)

“There’s a lot of respect with everybody that is here-from the parents, to the kids, to the therapists… Everybody kind of has this mutual respect for who you are, why you’re here and what you’re doing… I’ve been allowed to show them how I do it at home and what works for me and get feedback on that. Right off the bat (they) asked “What’s important to You? What do you think she is ready for? How do you think we can best accomplish that?”(caregiver of Allie)

“They’ve all been very kind… I mean I really felt the therapists had a very gentle, sweet approach. And even the way the physical therapist-right-that first day I remember- she was kind of the way she was asking questions of me- was almost like- through (my daughter…I knew it was a question for me-because (my daughter) can’t talk- but she would phrase it to (my daughter)-and it was just a nice way to kind of keep her involved and keep that gentle tone, and keep her feeling she’s being interacted with.”(caregiver of Danielle)

“They (the therapists) respect him… They listen to us…I see it (the therapists) as my family too- as part of our family- because they are to help us, they explain us what’s going on…They listen to us- and that’s what family do- right? They are there for us. We can call them, we can email them- and they are always there-I know help is there…they are really special people.” (caregiver of Fernando)

“Everybody’s so nice, and understanding and compassionate. And I don’t feel intimidated by the therapists who are here. They don’t treat the parents as if they’re the professionals and you are below them.” (caregiver of Allie)

Combined Effects

Statements from caregivers supporting the comfortable, relaxed environment and flexibility

“It’s a different environment. I think she realizes she is working- this isn’t my house and I can’t just go over here and play…I think-just the flexibility- there’s a real nice flow, it’s a very-easy going atmosphere. You know that you’re here to work very hard, but we have fun doing stuff. You know-we’re singing and we’re laughing and we’re playing with toys…It’s a comfortable, accepting environment. (caregiver of Allie)

“(a positive) I can mention- just the atmosphere-I think not just the building- but just the-you come and go when you need to- just like everything seems very laid back. Where you know- ok- I need to ask…before I can do this-Lunch being provided really helped-just- it kind of feels like- kind of like home-Where you can eat, if you want to grab something- go ahead-or-that kind of environment- was kind of helpful-very nice.” (caregiver of Bella)

Statements from caregivers supporting the value of having new therapists at the intensive program providing a fresh perspective with their child

"I think the top thing would be just the fresh perspective. I think sometimes when you have someone working with your child over and over and over again-all the time. I mean- that person may be excellent at what they do- sometimes just having a fresh pair of eyes, a fresh set of hands, a fresh set of ideas you know-that just that therapist maybe hadn't thought of- or so it's just the fresh perspective- I would say-to get new ideas." (caregiver of Danielle)

"You have so many different people who've seen and treated different things-their all bring their different angle of expertise to the table…it's great to get a new set of eyes on things." (caregiver of Allie)

"I think it's cool that he had different therapists- that you guys all come from different places- that you're not from here. And it's interesting- different areas do different things-so like perspectives." (caregiver of Holden)

"Get different ideas from all the different therapists that come here than just the ones you would regularly see in school or privately. You get a different perspective of what might work, what might not work-or if it would be easy or not. Try this or this thing works- this maybe doesn't – so it's a lot of bouncing of ideas around and stuff." (caregiver of Evan)

"We found out what- a few of the techniques they were using- wouldn't benefit him- so you get other feedback from people who haven't seen him day to day so that helps-a new set of eyes looking at him." (caregiver of Mitch)

"Just to get a second opinion- just second eyes- second hands." (caregiver of James)

"You're working with a different set of eyes or set of hands- and then maybe-if you know the child so well- maybe you might overlook some things. With a new set of eyes and ears-it might come with something that you haven't thought of before…I think the second opinion-or other ideas maybe you weren't thinking about before (is good)." (caregiver of Bella)

Fresh perspective with trying equipment is helpful to caregivers

"I always like it when you can try different pieces of equipment… It's kind of nice because this equipment is really expensive." (caregiver of Evan)

"I knew he needed some equipment and no one at home was getting through to me-us. And so yes- we have some ideas now- now we can run with this…I am a very visual person so I think actually showing us the equipment (was helpful)." (caregiver of Holden)

"This equipment, that you know-it's easier than me trying to figure it out myself…and we have a longer period of time to do it. Like the next day- come back instead of if you only see somebody once a week- then you have to wait a whole week before you figure out- whatever it is.” (caregiver of Chad)

Theme 3. Team collaboration as part of the intensive program was highly valued by the caregivers.

The majority of the caregivers discussed the importance and positive aspects of team collaboration used throughout the NDT intensive program. Co-treating with different disciplines including PT, OT and Speech therapists while involving the parents, outside therapists, and other caretakers were viewed as valuable. Caregivers suggested improved communication and direction providing a better picture of the whole child and their needs with this collaboration. Many caregivers reported having many disciplines working with their child, however the overlapping intervention times and co-treatment with extra handling was viewed as a positive alternative for delivery of services. Collaboration was also suggested by caregivers to improve functional outcomes for their child, and knowledge provided by all disciplines was greatly appreciated.

Combined Effects

Statements from caregivers illustrating the important value of team collaboration during the intensive program

“You’re part of the team, and your child is part of the team. Just everybody collaborates.” (caregiver of Allie)

“Their collaboration with each other has been very impressive. They each consult with each other what they’re trying to accomplish- what they’re trying to do. And I’ve observed that visually and verbally too. That impresses me. Because I feel like they’re both working in the same direction.” (caregiver of Kevin)

“The main reason we keep coming back is because of the collaboration between the therapists, and looking at the whole picture.” (caregiver of Isaac)

(I liked) “The multidisciplinary approach-right-all at one time so everyone can see the different components as they’re coming together.” (caregiver of Danielle)

(Top three things about intensive) “That its research based, it’s multi-discipline and it is collaborative.” (caregiver of Chad)

Collaboration of the three different disciplines: PT, OT and SLP

“The positive of just the collaboration of all the therapists- I feel like-it hasn’t been just (my son’s) treating therapists that have been working with him. We’ve gotten collaboration from you- from the others too.” (caregiver of Kevin)

“I think there’s been more communication, obviously between the therapists because they can-because they are in the same room with each other and that doesn’t happen as frequently with her regular program.” (caregiver of Danielle)

(At intensive program) “PT and OT and speech work with him all at one time. At home it’s just one time PT or one time OT…. Here you guys all corroborate (collaborate)” (caregiver of James)

“I’d really never seen co-treating before and I now really like co-treating.” (caregiver of Holden)

“It seems like the two therapists- they kind of have some overlapping time and they both work together with my child, and in the other-the regular therapy- it’s forty five minutes with this one, then forty five minutes with the other one. So I actually like the overlapping where they can kind of both problem solve together and kind of piggy back on each other and see what she’s doing, so how PT or OT can help OT.” (caregiver of Bella)

“They (PT, OT and Speech therapist) all worked together and talked to each other about him. So they were all getting each other’s feedback so that was nice-feeding off what the other person had to say and what to do and what to work on.” (caregiver of Mitch)

Child Effects

Statements by caregivers suggesting collaboration improves progress toward goal attainment for the child

(In previous therapy) “I didn’t see any progress with (my son). And he was there at (outpatient facility) for two and a half years…because we didn’t feel like he was getting what he needed in OT and Speech there…and there was no collaboration whatsoever- with all the different PT, OT and Speech.” (caregiver of Kevin)

“We were looking forward to having the collaboration between the therapists and really spending some time looking at the whole picture of (my son) and his development…looking at the whole picture and not just individual therapy goals but rather looking at how they all tie together to see a progression.” (caregiver of Isaac)

“These new therapists came in and asked questions and found out about (my son). And then-kind of took the information he was giving and the verbal information I was giving- and ran with it and figured out how they could help him, and figured out how his system worked." (caregiver of Liam)

Child Effects

With some children it is helpful to have more hands available for treating them effectively

"A lot more hands (is good)-See (my son) has always done better when you co-treat." (caregiver of Evan)

"Most of the time it is more than one person…in the intensive-to have two, four, six hands to start-to have him start-And so that is the difference of having this kind of intensive." (caregiver of Fernando)

Caregiver Effects

Statements that suggest knowledge was gained by caregiver as a result of exposure to "team concept"; amazing results with combining knowledge and collaboration

"Being at the intensive I learn a lot more and I need to learn how to explain because I need to really learn-(so)I can explain to talk to school better…Because I cannot always bring therapists to school." (caregiver of Fernando)

"With his PT- at one of the places we go to- I don't go back there (to watch therapy) and I really do think it is important because it is team building. This is-you can't have one person without the other." (caregiver of Holden)

"People are looking at stuff and doing stuff and giving me ideas of what might be a way or an easy way- like just having a sounding board of people being able to tell me things- or back and forth about what might work or what might not work and this would be a good idea…it's easier than me trying to figure it out myself." (caregiver of Evan)

"As much as we love our regular team of therapists-and they are doing wonderful things with (my daughter) too- I just feel like there were specific things that I just wasn't learning." (caregiver of Danielle)

"I think anytime I had a question or concern I think I brought it up and either they explained why they were doing what they were doing and I thought "oh, ok" or we changed how we were doing it." (caregiver of Allie)

Combined Effects

The value of collaboration for sharing information with others including outside therapists, assistants, teachers, and family members

"Our regular PT actually stopped in for a little bit and was watching the other day and telling them- these are some of the things that we are working on and this is where I'm having a hard time. And then they can all come together with a common cause and a common goal…We're all looking to benefit that child." (caregiver of Allie)

"Talking with the other therapists…And being able to then share that (treatment ideas) with the PTs and the OTs that he'll be seeing the rest of the year… It's good ideas to be brought back to the therapists that are seeing him now."(caregiver Evan)

"I like that it was arranged into OT, PT and Speech. I like that it had suggestions for not only at home but for the school district which I was very concerned about. I think that when I came in- I wanted something that could be implemented in the school." (caregiver of Chad)

*"*Especially for my husband who hasn't been here…there's pictures next to it-(the home program) so once again- it's a visual thing of (my son) doing it-and I think that will also help." (caregiver of Holden)

(My son) "has an assistant-one on one and to come to the intensive…she has a chance to work with him and those professionals watching and guiding her. So this is the important part." (caregiver of Fernando)

"His therapists and his teacher and his sitter already-yesterday I was talking to them on the phone and I already told them- ok, now we're trying this new way of transferring…So I already have those ideas to take back with us- that will help them in school." (caregiver of Kevin)

"So that's how I look- you know. My mom and my step mom and if our family is taking care of (my son)- it's just as good as me…and I feel like- we all have to have a part in (my son). Because when they baby-sit him- they have to know (what to do with him)." (caregiver of Grayson)

Theme 4. Collaboratively setting objective, realistic goals to improve functional abilities of the child was an effective strategy for goal attainment and highly valued by caregivers.

Goal-setting for charting individual progress is important to both therapists and caregivers. Individualized goals set collaboratively by the team important to the family and children are critical for motivation and progress toward goal attainment. Goals provide focus of intervention and objective measurement for the therapists, caregivers, and client. Goal attainment provided hope for the caregivers. Discussing expectations of the intensive program and setting goals were prioritized and valued by caregivers.

Combined Effects

Statements by caregivers supporting the importance of planning and having focused goals set collaboratively

“Come with goals in mind…so that was helpful to have already thought about those…to have that be thought out- and to talk to their therapists that they are working with. To get their input and to collaboratively come up with a plan.” (caregiver of Isaac)

“We had those two goals and they were very important for me to take care of him- his personal care and everything.” (caregiver of Fernando)

“Maybe there are several goals, which one do we want to focus on first. I guess it would be good for them (caregivers) to come with their three goals or goals they want.” (caregiver of Bella)

(the intensive program) it’s more focused on the goal- on the target that (we’re) trying to accomplish.” (caregiver of Kevin)

“Identify a need and break it down into measurable, attainable steps to which to succeed at-to reach a solution to that need.” (caregiver of Chad)

“Because- when you set a goal and we work on that every day- you have this- how can I say- what’s the word to use? Consistence- you work on the same point for five consecutive days.” (caregiver of Fernando)

Statements supporting the importance of realistic, objective goals to track progress of child and providing motivation for caregiver

“I think that I was glad to have the two weeks because based on the goals that we set- it would have been hard to see that be accomplished in a week-so I felt like the two weeks for us on the goals that we set were very realistic.” (caregiver of Isaac)

“Try to go in with realistic goals… I learned what realistic goals were and what unrealistic goals are…because I was a parent who went in with unrealistic goals in the beginning…. to maybe get some more functional stuff out of him-and that’s what I was looking for.” (caregiver of Kevin)

“When you set and have a goal that you know can be done-you look at your kids and see- he will do it. You have to be realistic- and the therapists that you have right now can help you with that.” (caregiver of Fernando)

“We had maybe a narrower set of- a more narrow set of goals then we normally do because I mean- there are so many things we need to work on so we selected a narrow set of goals…for us, the end product-we want her to be crawling… That helps me feel more motivated, I guess-to keep doing-working on those things-I mean how that component fits in with the bigger picture.” (caregiver of Danielle)

Child Effects

Statements supporting specific improvement or progress on functional goals and skills were important to caregivers

“Positively I would say- just being able to see (my son)-take a few steps independently with his cane.” (caregiver of Isaac)

“That was the first time-during this- it happened during his intensive. That was the first time that I saw him having nice sips from a cup.” (caregiver of Fernando)

“My realistic goals are you know- like for instance- now that (my son) is able to help with pulling his shirt off- that was a big thing for me.” (caregiver of Kevin)

“Be able to be more-independent in feeding herself… and she’s holding onto it and walking- she keeps leaning forward- so we want her to be able to be upright walking with her feet first.” (caregiver of Bella)

“He needs to stand. It helps with his weight bearing- it helps with his frustration…So he needs the help. Stepping up to his stander-giving him step when transfer from his chair or even from his bed to get to his stander. Then going up two steps- to standing there for half hour to one hour.” (caregiver of Fernando)

Statements supporting specific improvement or progress on components of movement including different system impairments and foundational skills are important to caregivers

“Strengthening is always going to be something with him and range of motion. Get him up and moving as fast as we can get him moving… I think what he wants-we probably both want- is just more mobility and sensory- like he already- we got that sensory component out of the way a little bit. He was so freaked out to just put any weight and to even walk on that foot at all without his brace on.” (caregiver of Evan)

“Where she gets a greater sense of what she is capable of doing and gets that input to know, hey-I can move my leg- I can take a step to try to cruise and yea-I think there –seeing her improve on some of the elements…We’re working on those specific components because that component is even more important in some ways- then the end product.” (caregiver of Danielle)

“To give him body awareness- and just beef up the skills that he had acquired- walking, and getting used to his body working as one… We need to bring attention to the left side of his body- he needs overall more body awareness-this is what we are going to do to help bring that along- prepping his body for all- just moving and exploring in a different way. Him using both sides of his body-it looks very different than him just using his dominant right side of his body.” (caregiver of Liam)

“He’s got- his balance has improved and his you know- leg strength and his gluteal muscles too- so everything to help him stand up. And arms- he noticed his hands now- He is noticing his body, his hands-and he’s noticing his feet-yea- body awareness.” (caregiver of Mitch)

“Our ultimate goal of course is to walk and that’s why we’re here-but there’s like little steps you have to take to get there. He’s learning the skills to just stand with balance. We have to have the foundation first which is what we’re here for.” (caregiver of Grayson)

“It wasn’t so much I wanted her walking on her own by the end of the week-it was I want her to have more control… Again- more of those building blocks to get us to that big goal.” (caregiver of Allie)

Combined Effects

Statements supporting goal attainment provides hope for caregivers

“We’re proud whatever he does-his accomplishments-his little baby steps that he does make. He’s doing small little progress-upwards.” (caregiver of James)

“For (my son) it’s to walk- and if you said on Monday that you want him to walk which is of course what I want- and then on Friday it doesn’t happen. Are you a failure? Absolutely not- but did you do all the foundational steps to get him to walk. Yes- so you can tick off- with little steps- and I think that is the way you have to look at it. What is my ultimate goal for (my son)? To walk-More importantly-to be happy.” (caregiver of Grayson)

“He was wheel-barrowing- or bear walking-or crawling-Bear crawling-On all fours…and we spotted it- and I asked her- do you think he could do that? And she said-let me see if he’s sturdy enough. And he climbed up the whole thing!..And I just kind of stood there in tears. Like-he could do that. And I’m not the type of person who is not going to realize how huge that is. That was a big positive moment for me- that he had come that far.” (caregiver of Liam)

“My goal has always been for (my son) to reach his maximum potential-and I know that- if I see that he can still do more- than I know he can still do more.” (caregiver of Kevin)

“Because you know before- you couldn’t get close to his mouth. He was getting hurt and biting himself for every attempt-every time he attempts to swallow-was scary for him and for us. And we don’t want to see that- but now we scored and he had from a cup- he had 9- today he could swallow 9 times to take from the cup…and we were very happy for that…he was enjoying his drink.” (caregiver of Fernando)

“I hoped we could make the progress to crawl…I mean-so those were those big goals. But I think the hope largely, or more broadly-the expectation or the hope was that we would learn new things, and that we would just make some progress toward what we’re working on.” (caregiver of Danielle)

Theme 5. Home programs with therapists teaching intervention techniques were viewed as essential for carry-over in the home and other settings.

The individuals involved in the NDT intensive program viewed education of the caregiver and providing home programming as fundamental to the success of the program. A hard copy of a power point with written suggestions and pictures of intervention ideas were provided to each caregiver participating in the program. All suggestions were reviewed by each discipline providing services for the children. The home program was viewed positively by all thirteen caregivers interviewed. Caregivers especially liked having the pictures of their children performing activities with the narrative to assist with carry-over from the intensive program to home.

<u>Caregiver Effects</u>

Statements from caregivers supporting positive views of home program and the importance of using it for carry-over at home for improved function

"I love it." (the home program) (caregiver of Liam)

"I'm very impressed with the home program and the power point…I think it's wonderful to be able to have the pictures with the written materials to share with therapists and school staff." (caregiver of Isaac)

(The home program) "That's very important. Because for our regular therapy-with that one week between we want to kind of make sure she does it two or three times before she goes back to therapy again and what she-what we pick up from here-we want to reinforce and follow through with at home-so she won't lose what she has gained." (caregiver of Bella)

(Top three things) "The collaboration- the feedback- the ideas, the suggestions to carry over at home that you can do-easy modifications, adjustments…that is not going to put a parent out financially or anything like that. Things that you can work with your own child at home-a way of being able to carry over the treatment at home to help- to facilitate and improve more of the outcome quicker." (caregiver of Kevin)

"The terminology-you guys didn't use "therapatized" words-words that we would understand-so when we're at home looking at it and reading about it, we'll understand it." (caregiver of Holden)

"They gave us the power point- with the pictures – and that's wonderful…we sat down with the therapists and they explained what they were doing again in each picture- explained or they had a little-paragraph with each picture explaining what they're doing." (caregiver of Mitch)

Combined Effects

Statements supporting being able to use the home program for educating family members and others involved in the care of the child

"Definitely with the verbal input with the therapists talking to me about ideas and suggestions- I've already called daddy and told him- ok- we need to do this, we need to do that- we need to put grab bars in the house so we can start doing and practicing at home…the support thing for his chair to help with the sitting, standing-you know those practice exercises and stuff." (caregiver of Kevin)

"The pictures help the parents a lot because you know- like what me and my husband say a lot is- we're afraid to –you don't know if you're going to hurt him- working with his muscles and stuff or stretching him- I mean with the pictures-it helps the parents work with him at home." (caregiver of Mitch)

"And it's helpful for people who don't know what to do with her…. So that people who were taking care of her- whether it was a nurse or her grandparents- or the babysitter- so instead of sitting around and playing with the same thing- or watching T.V.- they could grab the (home program). It also helped keep us, as parents, structure and following through with things we had worked on." (caregiver of Allie)

"(the home program is) very helpful. Because I think it is something that will help me-to help train future babysitters." (caregiver of Danielle)

Statements supporting being able to use the home program for educating other professionals involved in the care of the child

"His school team is looking forward to it (home program)." (caregiver of Liam)

"Getting the program-getting the video, the pictures, the booklet or whatever you would call it. And being able to then share that with the PTs and the OTs that he'll be seeing the rest of the year…It's good ideas to be brought back to the therapists that are seeing him now." (caregiver of Evan)

"They have to know how to stand him, he has a stander at school that took years for us to get. Now he has a stander at school so he can go to his stander after lunchtime –stand and that's how- that's what the home program's all about." (caregiver of Fernando)

"The power points-suggestions and you know you'll be able to take it to your therapists…I think it's great. Especially for my husband who hasn't been here-just to see it because now- there's pictures next to it." (caregiver of Holden)

Caregivers appreciated having a sounding board for carry-over at home

"People are looking at stuff and doing stuff and giving me ideas of what might be a way or an easy way- like just having a sounding board of people being able to tell me things- or back and forth about what might work or what might not work and this would be a good idea- or maybe ask about this." (caregiver of Evan)

"There's a lot of times when- I can sit there and look at him and I can't think outside of the box and stuff for him. So I felt like I needed that input from somebody on the outside to tell me what could work for him- and what would work- what would make my life easier to handle him." (caregiver of Kevin)

Theme 6. Roadblocks caregivers encountered in the delivery of intensive therapy services with insurance coverage and scheduling impacted their children's participation in the intensive program.

Many caregivers expressed difficulties with obtaining therapy they considered necessary for their child with a disability. Lack of insurance coverage and the price of therapy impacted the intensive program participation. Many families did not have insurance coverage and paid for the intensive program out-of-pocket. Many caregivers desired more therapy services for their children than they were currently receiving. Families expressed difficulties affording therapy for their children. Families shared feelings of frustration and worries from the lack of insurance coverage for current therapies for their children.

Other difficulties caregivers voiced as challenges to the participation of their children in the intensive program included logistical problems. Many families were not from the Milwaukee area and had to drive long distances to attend the intensive program. The time commitment for the intensive program was substantial and required advanced planning. Scheduling conflicts with caregivers' work commitments and juggling other activities of siblings of the participating children were also expressed as challenging by caregivers.

Combined Effects

Statements supporting financial constraints (private insurance; federal funding) preventing participation despite caregivers' perspectives that the intensive program is beneficial for their children

"I cannot do the intensive again in October. It is way too expensive and I cannot afford that. We have serious problems with the insurance program. They don't charge Medicaid-so I don't know where to go for this…if I have the ability to go to the intensive in October than that would be the goal. Because giving him that…That's what he wants to do." (caregiver of Fernando)

"We just couldn't afford it last year…and there was just no way we could do it and then he had (specific) surgeries and you know-we're always dealing with so much at one time. We weren't able to do it in the summer. But we saved our pennies and were able to do it in the fall." (caregiver of Liam)

"We asked grandma- because our funding-was very limited." (caregiver of James)

"You know the money portion is big for families…and then sometimes insurance- our insurance has never paid for it (the intensive program) but some insurance companies maybe would. I don't know- they're getting worse for everything. I can't-I don't know if anybody now gets it through insurance or not! I'm sure it's getting where it's going to get worse that way before we get better." (caregiver of Evan)

"He (the pediatrician) always wants to see what we're accomplishing and thinks that the (intensive) program is very beneficial and has actually sent letters of recommendation to our insurance company-explaining what's going on and how much it is needed." (caregiver of Allie)

"I mean- wow I'd love this kind of a program all year around and for insurance to accept it. His insurance does not cover this." (caregiver of Grayson)

Combined Effects

Statements illustrating feelings of frustration and worry from caregivers from inability to afford therapy services the caregivers feel the child needs

"I called our insurance and I called our-the various state providers…and everyone we talked to gave me a different answer." (caregiver of Chad)

"We've been denied private insurance-and told never to be contacted again because of (my son)…So I have to have a job. I don't need a job- I have to have a job in order to provide the insurance…He's getting PT and OT- and then my insurance allows 40 sessions with PT, four OT a year total- ridiculous- for a child with CP. I mean- what do they want? A disabled child in their system their entire life? Figure it out- give him what he needs right now so we can move on- anyway-so that's my frustration." (caregiver of Grayson)

"Right now he only gets PT and speech- we can't afford OT…We need more money for therapies…and then we worry about next year and what next year's going to bring with the new health care reform." (caregiver of James)

"And that's the thing. My son only gets PT once a week. And we have insurance- we have great insurance from my husband's work. And he also has Title 19 for being considered disabled through the state…but yet-it stinks how they-what they approve him for. And yet I see other kids in the facility- that don't have as many problems as my son-and, and get approved for all this therapy. And I see them jumping around and here- my son's two and a half- and can't even walk. It's very, very frustrating." (caregiver of Mitch)

"It's amazing the stuff that gets covered and the stuff that doesn't. I mean-still to this day with all my experience with that- and years and all these EOBs and I still don't understand what they're all doing. You know because I've had parents go- can you help me with this? And I'll be like-I'll try my best. But sometimes I'm like- I have no clue why something gets approved. And then some stuff-I'd say there's no way they're gonna do that." (caregiver of Evan)

"Parents can't afford this. The price of therapy now-is- it's outrageous. I just don't understand how they can…. And these kids need it. And they thrive so much from getting this-that it's so sad when they're not able to get it because someone gets a piece of paper and says- "no-denied". That's how it feels." (caregiver of Mitch)

Combined Effects

Statements from caregivers demonstrating a desire for changes to support the delivery of therapy services like the intensive program for their children

"Keep doing it (the intensive program) absolutely- anyway they can. And figure out a way for Title 19 to pay for it." (caregiver of Liam)

"That's a chunk of money (required for the intensive program) and insurance doesn't cover it…I wish more people could benefit from it." (caregiver of Allie)

"They need help- to continue this program; Every single family who is willing to try-if they want- to just pass on- to be knowing- and to just see how much it can help. And maybe someday you have insurance companies that would pay for that so we would have more people coming. More therapists, more therapists being trained to help the families better." (caregiver of Fernando)

Caregiver Effects

Statements from caregivers supporting the significant time commitment for the intensive program; the tiring/exhausting effects for kids and exhausting/stressful effects on parents

“The hardest is the time commitment and the planning... Having to be here for the two- well it’s more- by the time you get loaded in the car and get here and get home-the time-it’s the duration – it’s just-you know- we pretty much had to put our life on hold with everything else-with the other kids, with my schedule and what I needed to do to take care of things- that nothing really got done this two weeks…and the two older- definitely for our whole family. The kids weren’t able to do things at certain times because we had to be here and so it affected the whole family.” (caregiver of Isaac)

“A total life commitment for that two weeks to participate.” (caregiver of Isaac)

(the intensive program) “is exhausting. But it’s also very motivating.” (caregiver of Liam)

“It’s exhausting for him- so we definitely plan to allow him some time in the afternoon and evening -not plan extra activities, extra running. We definitely cancelled all of his therapies and anything extra-curricular things he had planned for the two weeks.” (caregiver of Isaac)

“It is a period of time-You tell yourself for-ten days or twelve- whatever- and then it will be back doing- so you get organized and you get the help you think you are going to need. And it is very hard- like the first time. Because I came home and I had to clean the house! I had to make dinner. It was terrible. It just doesn’t work- it’s exhausting-I can’t do everything.” (caregiver of Fernando)

Caregivers’ statements supporting sacrifices including long drives and hotel stays for their child to participate in the intensive program

“I thought we’re going to be super close to where the intensive is offered, but it didn’t work out that way-so we’re not moved yet. So it’s just- by getting her up, getting her something to eat, and then trying to be in the car by 7:30, to get him (sibling) to his school program and get here.” (caregiver of Danielle)

(Drove one hour each way for first year of intensive)
“The first year we spent- we lived- I think the first two years- we lived two hours- one hour away so we were driving back and forth an hour each way. So just that- was even harder (as compared to this year living closer to intensive program).” (caregiver of Isaac)

(Drove one hour each way for this intensive)
“(where) He goes to school is five minutes from here so I’m used to driving the hour…It’s a typical public school. They just happen to have this fantastic program.” (caregiver of Liam)

(Drove an hour and a half each way to this intensive)
“The drive was the least of my worries. It definitely was worth it.” (caregiver of Holden)

(Drove five hours and stayed in hotel for five days)
(We) know way in advance when the courses are going to be- and October is the best time for us-anyway with our summer scheduling.” (caregiver of James)

(Drove from another state and stayed in hotel for five days)
"I haven't felt like it's been- it hasn't had an effect on (my son's) treatment in the long run…he's done pretty good (driving in car and being in hotel)." (caregiver of Kevin)

Caregivers' statements supporting logistical planning and advanced scheduling is required and can be challenging

"I normally work three days a week, so I just changed my work schedule so that I was working in the afternoons for pretty much and for longer days for four afternoons. So, I was leaving here- so I guess scheduling-logistically maybe was a little bit of a challenge." (caregiver of Danielle)

(the hardest is) "Just the scheduling. Rescheduling and keeping everybody scheduled… I mean it's just a lot of rearranging with stuff, because we have one- he has a brother…It's logistics of it all…We just do the summer one-because of school for him at this age…now it's really tough for him to miss that kind of school." (caregiver of Evan)

(the hardest is) "I would say for the most part it's scheduling…(work) and other siblings too- so- scheduling." (caregiver of Bella)

Theme 7. There's no cookbook answer; each child and family is unique with different strengths and difficulties. Intervention must be based on individual needs and abilities of the child with the disability and family.

The data revealed the caregivers had strong opinions about the therapy services for their children. They identified strengths and difficulties sharing unique qualities of their children and families. Caregivers discussed dissatisfaction with delivery of services for meeting the needs of their individual children. Opinions were shared frankly by caregivers about differences between a variety of therapy settings providing services.

Strengths

Caregiver Effects

Parents have hope and realize their children are unique

"Parents always have hopes for their kids. But you know, (our son)- we're proud whatever he does-his accomplishments-his little baby steps that he does make." (caregiver of James)

"We want to try to hold out hope…I know there's no magic bullet out there for any of this-and it takes- it all takes time." (caregiver of Danielle)

"None of it is an immediate sort of thing. It is one of those things that she processes for awhile and then all of the sudden she'll just start doing it on her own later on when she's ready." (caregiver of Allie)

"It's up to him- what he can do." (caregiver of Mitch)

"He'll walk correctly-maybe in 8 years- maybe in two." (caregiver of Grayson)

Validating child for who he/she is and where they are developmentally- children are gifts and caregivers feel blessed

"In general we count our blessings. Because she's very sweet, and she is working hard, and she is making progress." (caregiver of Danielle)

"I'm blessed- he's my baby. He's a gift- I cherish him- you know he's a great baby- he's a great kid…but all parents think they're kids are-but he's a good boy." (caregiver of James)

"It just was very motivating and emotional for me to see the kids that are here… I think I felt – blessed. That he's doing as well as he is." (caregiver of Liam)

Child Effects

Statements supporting caregivers are strong advocates for their children

"I really liked that they asked me questions and realized that- I just kind of don't sit back (laughing)-I'm really in it with him." (caregiver of Liam)

One parent attends school with her son:
"But I do his suctioning and I feed him-at the school. Yea- I stay in the hallway-I sit in the hallway waiting-for him…At first when I told them that- because he was a trach child and needed a nurse on staff with him at all times- and they said- we have a nurse so we won't give him a private nurse with him and I said- uh uh- I said he has to have a nurse with him- that's what I was always told by the doctors in the hospital- that he has to have a nurse at the school when he's being trached-and they said- no as long as we have a nurse on staff here- that's all we need- and so I said I'm not leaving him- I'll suction him, I'm going to feed him, I'm going to do this-and they said fine- so I had to be fingerprinted and everything to be able to be at the school- so I'm at the school with my son." (caregiver of James)

"I resigned by job to be able to be with him 24/7 because of these extensive medical needs." (caregiver of Chad)

"So I had to fight every time I went to a doctor…his nursing staff fought me the entire way about it-and I told him- I said- Dr.(physician's name)- just to let you know-your nursing staff wanted me to sit- in the waiting room. And you told me- if you want your children to survive and be happy and healthy- never, ever sit in a waiting room." (caregiver of Grayson)

One parent went back to school to be therapist:
“I enjoy it- I like it. and I’ve- I think I’ve helped out a few parents now- that was my ultimate goal was for parents to be able to understand that-what the benefit is of therapy for their child and what the benefit is of being consistent with their therapy.” (caregiver of Kevin)

Child Effects

Statements from caregivers illustrating the importance of increased social interactions for their children

“It is very important for him to participate in lunch, you know-to be in the community.” (caregiver of Fernando)

(it is important for him) “To have a friend his age. Instead of always be friends with the little babies, and friends at day care-It is so big-it is so huge for (my son) to have somebody his age….I think for (my son) it’s also socialization- of being just normal here (at intensive program).”(caregiver of Grayson)

“Because he likes people- so this (the intensive program) is a social thing for him…hopefully he’ll get more friends- because this is his first year at this school.” (caregiver of Evan)

“So having other kids- other kids for them to interact with especially during playing pretend or something-they have other kids they want to play with- it keeps them going.” (caregiver of Bella)

Difficulties

Caregiver Effects

Statements supporting it is sometimes exhausting for parents advocating for their children with disabilities

“It is exhausting.” (caregiver of Liam)

“And sometimes we don’t have the energy anymore. Like it’s if you ask me one more time- like I tell a friend-I’m like-she was fighting for something. And I’m like- yea- like you’d really want to fight for that? Like you want to spend like-what was she spending- five hours a day on the phone trying to get this piece of equipment.” (caregiver of Evan)

Parents get tired of therapy

“And I’m just here and we have to involve the parent- well-that’s fine-I give you permission to whatever you want to do- you know because sometimes it’s like- I don’t know- why don’t you guys just look and see if you can come up with some ideas- because mom’s burnt with doing this therapy stuff.” (caregiver of Evan)

Specifically dealing with the medical diagnoses and disabilities of the child can be difficult for caregivers; they grieve about a future that will not be

"There are moments where you maybe, I see a little toddler running or something like that and I wish that she could be doing that by now- well-or at least walking."(caregiver of Danielle)

"I think the CP part. And it's different for my husband-he has a harder time with- he had a hard time with the CP-and I had a hard time with the hearing loss-so we were the opposite of each other…I know what it's like-to look at somebody else's kid and want my child to do what they're doing." (caregiver of Liam)

"I mean you'll always going to come up against that sort of grief around the situation at various developmental stages-so like for (another parent's) daughter…one mom I think it was like when her daughter wasn't at the prom or with the other mom- I think it was when her daughter was in high school. So these were moms whose children were older-who had gone kind of through this…There are those moments when you do have that kind of sense of-I wish you know, or why can't she be normal?" (caregiver of Danielle)

(after diagnosis was given) "I cried myself to sleep for three weeks." (caregiver of Liam)

"We don't know what the cause of (my child's) problems are- and I've sort of come to conclude that probably even if you do know the cause of the problem- you still- it isn't always easy to accept." (caregiver of Danielle)

"It is always very hard. It is stressful and exhausting." (caregiver of Kevin)

"He is a normal child- but he's not a normal child. There's a lot of medical issues and we have to worry- is he gonna be ok?" (caregiver of James)

Caregiver Effects

Statements suggesting intensive therapy can be stressful for caregiver

"In the beginning those first days I guess I was stressed because I was a little worried about whether it was too much for her-or it was overwhelming- and then-I don't know- or if I just wanted her to perform. Or get all kind of ideas. I'm not sure-but I just-I felt a certain tension." (caregiver of Danielle)

"It's always a mom's worry- they're pushing him too much." (caregiver of James)

"We came back from a walk and he was screaming- but we got him calmed down in a few seconds- you know-it made me sad….But it's hard as a mom- it's a hard stressful thing as a mom." (caregiver of Grayson)

Combined Effects

Statements supporting the need to recognize limitations of families and the children (including individual and contextual barriers)

(Individual barriers)
You know-at different parts and times of our lives- like when his brother was a baby- there's just different times when things were easier or harder." (caregiver of Evan)

(dealing with difficulties) "But I think we've adjusted to that. And then last week there was one morning when we didn't come because I mean-she also was having problems with constipation…I guess that's how we coped with it-with the difficulty we just skipped one day." (caregiver of Danielle)

(we've had) "alot of difficulty with going to school, trying to get boots on, trying to get on the bus, trying to overcome the fear of a new bus driver when he would lay on the ground and scream and holler and kick his feet." (caregiver of Chad)

"Depending on the age of kids you've worked with- you realize, yea, there is an age where -you really need to start asking a lot more to him and what he wants-what he's comfortable with all the way through…(My son's) been getting friends through Special Olympic swimming so that's been good-the team group thing he does-that type of thing-so there are different avenues- but it's hard because then everyone else has the rest of the family and the kids have different needs." (caregiver of Evan)

(Contextural barriers)
"They're always pushing me to get a lift at home- but you know- we don't have the room." (caregiver of James)

"And what happens too is- he just can't naturally go over to someone's house because he's got his walker." (caregiver of Evan)

Caregiver Effects

Statements from caregivers supporting the value of networking and being with other caregivers of children with special needs (not feeling so alone)

"I meet new people and we learn we have more things in common…I think it was cool too that- (two boys in the intensive)-his buddy- played together-like a little play date for moms." (caregiver of Holden)

"I think if there was somebody that could just- like a parent-that's been through it-could come and hold your hand- and tell you- and you can ask me questions-and whatever- just to know- you're not alone- I think that's really, really important…People have no idea what to say. So it was very refreshing to me to sit and talk to two of the other moms here and have them just not give me that look- to understand where I was coming from… You have this common bond- that other people just don't get. Sometimes you don't even have to say anything." (caregiver of Liam)

"That social element just for any parent out there who thinks, gee- I don't know anyone else who has a child with special needs, I think that when you do meet other parents, or see other situations-you don't feel so alone and it might even put your own situation into perspective to some degree. You know- it could be worse…I mean- so-the talking to other moms I think has been helpful-to me- to just give me some perspective on things." (caregiver of Danielle)

"I think this is a really good learning experience-for parents and it's also- you actually get to meet other parents who have this-I think when you're out in the real world- you look for- there's another parent that has- a child with special needs. You know- you look for that…like can anybody else relate? And here you come in and it's like- not – you can't compare- but you can exchange notes-you can say-I've been through this- or you can do this… so I think one thing is for parents to bond." (caregiver of Grayson)

Combined Effects

Statements revealing caregivers opinions on therapy services for their child varying in different settings

a. Dissatisfaction of home (Early Intervention-EI) services compared to clinic visits

"We were in the home until May I believe and then we transferred to clinic which has been a-a very beneficial change for us. Much better (private therapy in clinic) It's a different environment. I think she realizes she is working- this isn't my house and I can't just go over here and play…I also think that the equipment that they have there and the space that they have and just the variety of things that maybe I don't have at home. It was a kind of a change of work out for her- mix things up and it worked out very well." (caregiver of Allie)

"Birth to three you mean? Well, I-it was awful…This was all new to me- obviously-so when they first came in- I was just like-oh, ok this is good. Nice having them come to your house. But, as I got to see what (private therapy in clinic) has done for us-and how unaggressive they were with birth to three. And if he was tired- or crabby-they would leave-they'd say-oh- he's not having a good day- and he wouldn't get any therapy. So- here (at intensive program) they work through it. They work through his sleeping, they work through his crabbiness…. (EI services) It made me mad and sad." (caregiver of Mitch)

b. Statements supporting dissatisfaction with School therapy

"And so far they've been all good- besides his school…Just with some of the therapists- sometimes-if he doesn't want to feel like working-I don't know if he gives them problems- or if they get frustrated because he's not cooperating with them…School- sometimes-we'll try it and if it doesn't work- that's it- they only give it a one time go…The school- doesn't give him that chance-you know they want him to calm down by himself." (caregiver of James)

"We've only had therapy in the school and we've not participated. As parents-guardians- we've never been included in his therapy…Those evaluations and reports (from school) are very, impersonal-compared to-what's given here." (caregiver of Chad)

"The school starts calling me-to pick up my son because he's not doing anything-he's lying down on a mat." (caregiver of Fernando)

Statements from caregivers supporting dissatisfaction of therapy due to limited services

"I don't think he gets enough (therapy) through school either." (caregiver of Holden)

"Being once a week for one hour- and watching what a therapist was doing- was not enough any more for me." (caregiver of Fernando)

"In school- it's 30 minutes for PT and OT and speech- but that 30 minutes includes- it's with 15 minutes of classroom time- so actually- he's only like getting 15 minutes prior to it and 15 minutes of classroom time with the kids." (caregiver of James)

Textural Descriptions

Perceptions of the intensive program experience were individualized. Reviewing individual textural descriptions provides insight for understanding "the big picture" of the experience with each caregiver. Including verbatim examples, further thoughts and feelings of the caregiver's experience can be explored. Individual textural descriptions provide the researcher insight answering "what" the caregivers experienced with the intensive NDT program.[2, 3] A textural description from one caregiver at the intensive program (Isaac's mom) is provided as an example.

Individual Textural Description

Isaac's Mother's experience of the intensive program was positive. Isaac was six years old and had attended the intensive program previously. For this intensive program, Isaac was seen by all three disciplines, and he attended the two week tract of the intensive program. He missed one day during the first week of the two week session. Isaac had a nurse and his Mom attending the majority of the sessions. Isaac's diagnoses consisted of spastic quadriplegia cerebral palsy (CP) and dystonia from periventricular leukomalacia (PVL) with greater involvement on the left side, seizure disorder, gastroesophageal reflux (GER), and hypothyroidism. Isaac functioned at the GMFCS Level IV. A Gastro-jejuneum (G-J) tube was used for nutritional needs and an assistive augmentative communication (AAC) device was used for communication. He was the youngest in the family and had an active older brother and sister sometimes involved in the intensive therapy session.

Isaac's mother was very satisfied with the organization, goal setting and care of Isaac during the intensive program. She continued to attend the intensives because of the "collaboration between the therapists" with the team looking at "the whole picture" with Isaac.

She was pleased with Isaac's participation putting "the schedule together." Her hope was to "see progress" in the goals set collaboratively with herself and the therapists. One of the goals for Isaac was working on "using a cane or other device less cumbersome than a walker." Isaac usually used a wheelchair for transportation and long distance mobility. He was able to walk with a walker short distances with close supervision, or without the walker with his mom's or nurse's assistance holding his two hands. For Isaac, using two quad canes to walk would provide greater flexibility and mobility (e.g. stair climbing) than a walker. Isaac's Mom was pleased with Isaac's improvement with balance and independent steps using the quad canes.

She was excited about having collaborative goals and enjoyed seeing "progress made toward reaching those goals." She liked having "very specific goals in mind" of what was going to be "accomplished during that therapy session." She felt the focus on working toward components for independence with all three disciplines was an integral part of the intensive program.

Isaac’s Mom shared insights into the difficult logistics with committing to an NDT intensive program. She explained “the time commitment” of intensive therapy for two weeks required putting “life on hold” for that period. “To some degree” it was difficult with the physical logistics of getting Isaac in and out of the car, but greater difficulty was with the family’s scheduling demands. “Nothing really got done this two weeks.” She reported the other two children were unable to participate in some activities at certain times “because we had to be here”, but she also stated “not that I would change that for anything” to be at the intensive program with Isaac. “We feel it is important enough to do that and to adjust the schedule accordingly.” She described the best way to deal with the logistical challenges was “planning” in advance.

Pleasure on how hard Isaac worked during the intensive was expressed by Isaac’s mother. She felt the goals were realistic for a two week period and progress was made with all the goals. She did state the intensive was “exhausting for him”, and extra activities in the evenings were kept to a minimum during the intensive program. He was just at home in the evenings “taking it easy.” She expressed having extra help and hands from the nurses working with Isaac have “helped me tremendously.” She realized “not everybody has the wonderful chance to have that.”

Dissatisfaction was shared with one aspect of the intensive program. Although “there was some progress made in speech,” Isaac did not receive as much practice as hoped with his speech goal of initiating peer interaction using the augmentative communication device. Only one or two additional children (not participating in the intensive program) were present each day at the program making it difficult for more opportunities for increased socialization and peer interaction practice.

One of the easiest parts about the intensive program for Isaac's Mom was watching how Isaac improved with the increased intensity. She liked being involved, learning, and enjoyed being able to sit back and watch others sometimes working with Isaac. She voiced the intensive program was different from other traditional therapy because with traditional therapy there is a week break from the next time Isaac has therapy. "The goal might be lost or what you were working on is no longer relevant and so you don't pick up where you left off." She felt with intensive intervention "you have carry over" day to day and "that's when you get to see more intense progress." Regarding Isaac and his family, "we go through so much in a week. That by the time we get back together after a week has passed- that's a huge amount of time."

Isaac's Mom reported she was very pleased with the therapists working with her son in the intensive program. She felt they were "wonderful" and had a great "desire to help" bringing all the information together with ideas for the caregivers. She appreciated time spent for teaching so there was good understanding and even "specific guidelines" helping to implement the recommendations within the family's daily lives and routine. She specifically remarked about the home program for Isaac: "I'm very impressed with the home program and the power point." She felt it provided appropriate suggestions for Isaac and caregivers to work on at home. She thought the pictures were "wonderful" with helpful written materials to share with others including private therapists and school staff.

Lastly, Isaac's mother summed up the intensive program as "a wonderful experience." She felt it was a very positive experience for Isaac and the family and she would "recommend it to anyone."

Structural Descriptions

Further insight can be gained by examining the structural description; the description of "how" the experience happened. The underlying dynamics of the personal experiences of caregivers interviewed regarding the intensive program were explored. The setting, context and specific qualities of the program accounting for "how" thoughts and feelings surrounding the experience with the intensive program were formed revealed the deeper meanings of the intensive program experience.[2, 3] Similar to the textural description, a structural description from Isaac's Mom is provided as an example.

Individual Structural Description

Isaac's Mom was the parent of a busy, active family of three children with Isaac as the youngest. She had a clear sense of Isaac's abilities and difficulties and was an excellent advocate for his care in all settings. Her enthusiasm for the intensive program seemed to be from positive past experiences, and dissatisfaction with therapy in other settings when goals do not take into account "the big picture" with Isaac.

Isaac's care may have been slightly different than other children with disabilities participating in the intensive program; he was the only participant with nursing care. Isaac's Mom expressed gratitude for this fortunate situation, and she acknowledged many others are not provided with this help. She expressed less stress and improved ease of care with Isaac since two nurses have been involved with him. The added nursing care has also made attending the intensive program easier.

She was also aware of the financial commitment required for many to participate in the intensive program. She had mentioned the program to others in the past but also is cautious because lack of insurance coverage and financial coverage can exclude many others from participation. Limited resources might inhibit others from attending the intensive program and Isaac’s mom was well aware of this. She believed the intensive program was beneficial to Isaac and financially worth the monetary sacrifice and physical effort to attend as demonstrated by past attendance and ongoing plans to continue with the program in the future.

Isaac’s Mom was very involved with Isaac’s care. She was proud of his hard work with all activities, and this was evident in each therapy session. She had specific ideas for realistic, functional goals for Isaac. She provided assistance with motivation for her son and the entire family participated in some aspect of Isaac’s therapy sessions.

Lastly, examining the setting and context of the intensive program, Partners for Progress (PFP) was started by two well-respected NDT pediatric instructors in the Milwaukee area. It would be remiss to not acknowledge the expertise and respect already provided to these therapists. Because of their association and work with the NDTA, other NDT experienced therapists were willing to assist with this intensive program. The program provided both a learning opportunity and beneficial collaboration for the therapists involved with the intensive program. The environment was unique because the therapy took place in a church environment which afforded different opportunities compared to a clinical environment. For example, there was less of an “office visit” atmosphere, and more flexibility with no “back-to-back” patients on the time schedule. Food was provided by PFP, and an open lunch time also contributed to the comfortable environment spoken about by many caregivers. Due to the pleasant personalities of both the PFP founders and many therapists working in the intensive program, the overall atmosphere remained calm with a positive, flexible tone throughout the weeks of the intensive program.

Textural-Structural Synthesis

The final step of a phenomenological study often involves integration of the composite textural and structural descriptions. Textural-structural descriptions incorporate the revealed themes of the intensive program and represent the meaning and ultimate essence of the experience.[2, 3] In the following section an individualized textural-structural description is provided first to create fluency with Isaac's Mom. A composite textural-structural description representing the essence of the experience for the entire group of caregivers is then provided. Verbatim examples are quoted with important phrases italicized.

Individual Textural-Structural Description

The intensive NDT program was a positive experience which Isaac's Mom would "*recommend to anyone."* The *time commitment* was significant for a two week intensive program "*affecting the whole family",* but the benefits outweighed the difficulties. It was a priority for Isaac and his family; "*important enough to do and to adjust the schedule accordingly."* Isaac's Mom felt the NDT intensive program was a *wonderful, valuable experience,* and she would like others to be able to benefit from it.

The experience of the intensive program involved meeting the needs of Isaac's caregivers for more information and instructions to help in their daily routines with Isaac. *The education part* of the intensive program provided recommendations and suggestions to help Isaac "*within our daily schedule."* Helping the family *to carry it over at home,* and being sure the caregivers understood the suggestions were a priority for the family. Isaac's caregiver discussed the hectic schedule of a busy family and for Isaac specifically, *"with medication and feeding and appointments."* Having a home program combining *"three or four things that are good at one time"* worked best for the family. Specifically, a power point presentation for the home program with pictures and written suggestions were helpful for all professionals treating Isaac so the family could take the materials *"to share with therapists and school staff."*

The intensive program provided focused *collaborative goals*; an aspect valued by Isaac's caregiver. Specific goals were discussed to assist with functional independence "*looking at the whole picture"* with Isaac. The three *specific goals* for Isaac included improving hand stamping of his name on papers, using the augmentative device for conversational speech and peer interaction, and using quad canes for walking. Isaac's caregiver was pleased with *progress made toward reaching those goals.* Collaborative intervention was provided by PT, OT and Speech therapist *"really problem solving to get to the root of the problem"* while working together for a single purpose or focus on one specific area of need. Suggestions were provided by all the therapists treating Isaac *"to continue that progress after we leave."*

Isaac's caregiver expressed one of the main reasons the intensive program is highly valued by the family "*is because of the collaboration between the therapists."* Having the PT, OT and Speech therapists working "*to bring it all together"* is of great importance and seen as a benefit to Isaac. *The "therapists were wonderful"* and exhibited good handling skills and a *desire to help* both Isaac and his caregivers. The collaborative efforts of the therapists *looking at how all things tied together* for helping Isaac was greatly appreciated.

The intensive program differed from the traditional therapy Isaac usually received regarding the frequency and duration of the therapy. Traditional duration and frequency of therapy for Isaac is weekly therapy: "*PT, OT is an hour and speech is forty five minutes."* Isaac's Mom recognized with *"traditional therapy you usually have a week break"* in between the time Isaac has therapy again. With the intensive program the therapy continues the next day. She reported "*the carry over is what is the main thing that is different"*, and she considered this beneficial for Isaac. She reported "*being able to see carry over from day to day"*, and expressed the significance of this linked to increased intensity of intervention. She related that with the intensive program you resumed where you left off the day before-"*you don't lose anything in between the weeks*."

Lastly, for Isaac to participate in the intensive program, much logistical planning was required. The program was a lot of work for the participants and even their families. The children in the program were fatigued by the end of the day. Isaac's Mom shared *"it's exhausting for him.*" For Isaac's participation, extensive scheduling was required for the parents, siblings, and nurses. Families often rearranged their entire schedules including work, sibling routines, and extra activities. Other outside therapies were cancelled for Isaac and routinely cancelled by families participating in the intensive program. The schedule was tiring for parents and "*extra help and hands"* available during the intensive program experience decreased the exertion and stress.

Although challenges were present with Isaac's participation in the intensive program, his caregivers considered it to be worth it. Isaac's Mom reported *"I just think it is a wonderful experience."*

Composite Textural-Structural Description

Discovering the Meaning and Essence of the Intensive Program Experience

The "essence" of the experience of the caregivers regarding the intensive NDT program is captured by examining and incorporating both the textural and structural descriptions.[2, 3] Key phrases capturing the meaning and essence of the intensive program are italicized with quotations used from verbatim examples in the following composite.

Caregivers have many concerns and decisions regarding the optimal therapy for their child. Each family has unique needs, concerns, strengths, and difficulties. An intensive program is one option for providing increased therapy in a short period of time. Although attending an intensive program often required extensive family scheduling and was expensive, caregivers viewed it as "*worth it and beneficial for the child.*" Both the caregiver and their child seemed to reap benefits from the intensive program.

Caregivers liked the *continuity of therapy* with the intensive program. Children were able to continue with intervention the next day beginning with skills they achieved the day before and working from this point rather than waiting a week in traditional therapy models. Caregivers expressed *improved carry over* and felt like *gains were not lost* in between the weeks. The therapy was *more aggressive*, and expectations were met quickly. The *repetition* with the intensive program allowed more practice for the children to assist with goal attainment.

Using a *collaborative model* in therapy was important to caregivers. Families expressed the opinion of having PT, OT and Speech therapists *working together positively impacted functional outcomes* for the children. It was vital for caregivers to have all individuals working with the child *on the same page* and striving toward realistic goals. Having all disciplines *looking "at the whole picture" of the child* was imperative. Caregivers wanted to be part of the team and viewed themselves as an integral link. Families felt *empowered having a voice* and sharing involvement with their children. Caregivers included teachers, other therapists, assistants, physicians, grandparents, siblings and other family members as part of the collaborative effort helping their children. Many families of older children shared the improved effectiveness with collaboration having more hands available for direct therapy of their children. Caregivers viewed the s*haring of information and communication* as vital for optimal collaborative treatment of the children with disabilities. Amazing results from the *exposure of combining knowledge and collaboration* were discovered.

An essential aspect of the collaborative effort during the NDT intensive program included *home programming*. Parents and family members wanted to be able to maintain gains achieved during the intensive program and were *excited* about receiving *suggestions for carry-over at home.* Caregivers expressed appreciation for the therapy home program using *both pictures and written narratives to explain the intervention ideas*. Many families expressed fitting these suggestions into the *daily routines* of their family and appreciating detailed ideas for *"what we need to work on at home*." *Sharing the home program* with the many individuals working with their children including babysitters, grandparents and other therapists was a priority for most families. Home programming *empowered* caregivers to assist their children toward more functional independence*; "I think everybody feels good when they accomplish something."*

Having *focused, realistic goals were highly valued* by the caregivers of children participating in the intensive program. The goals needed to be appropriate for the intensive program time frame and were set initially in a *collaborative effort* between the therapists and caregivers. Including families' ideas and priorities for these goals were a positive *motivation* factor. Tracking progress toward improved function was vital for all therapies. Objective goals kept all involved in the intensive program *more focused in therapy toward improved function* throughout the intensive program. Caregivers and therapists noted progress toward the written, quantitative goals. In addition, caregivers and therapists *observed and voiced improvements in qualitative aspects* of the child's movements. Observing the child make significant progress in the intensive program *provided hope and encouragement* to the caregivers. Setting *objective,* *realistic goals were viewed as a positive strategy* to assist with functional improvements during the intensive program.

Even with appropriate goals, many caregivers *voiced frustration* over obtaining what they felt was an *appropriate level of therapy services* for their child. Caregivers encountered difficulties with financial funding for increased frequency of services including the NDT intensive program. Caregivers discussed the exemplary quality of NDT services. Many caregivers desired more therapy services for their children within the traditional model than they were currently receiving. Even with *"great insurance"* frustration was voiced with receiving insurance approval for more therapy. *"Parents can't afford"* the therapy the caregivers believed their children needed. Parents *worried* their children were not receiving adequate frequency of services, and *disappointment and frustration* was expressed when parents felt a substandard level of professional expertise was given with some of the services received. Specific complaints were voiced regarding insurance coverage and federally funded programs.

In addition to difficulty with obtaining and funding therapy, caregivers have a variety of other *roadblocks and hurdles* when advocating for their child with special needs. Taking care of a child with a disability can be *physically and emotionally tiring. "It is exhausting"* caregivers reported. Even the intensive program was tiring for many families. Many children are dependent in their activities of daily living and require physical lifting. Other siblings and family members require attention and daily routines and lives can be complicated. *Extensive planning and scheduling* was required to attend the intensive program. The time commitment was substantial: *"a total life commitment"* during the time of the intensive program for participation. Although logistical planning was required, the intensive program was viewed positively as an alternative to traditional therapy. *Parents get tired of therapy* especially when the child is older and has required many therapy disciplines for many years. The intensive program provided a positive option in goal attainment from a short, intensive burst of therapy. The NDT intensive program also provided the family a *fresh perspective* from different therapists.

Besides logistical planning for the intensive program, other more complicated emotional issues about their children with disabilities were voiced by caretakers during the intensive interviews. Many caregivers were *grieving* medical diagnoses or set backs; *"I cried myself to sleep for three weeks"* one caretaker shared when an initial diagnosis was received. *Fear of the unknown and worries about the future* of the child were expressed by many caregivers. A few parents voiced *feeling stressed wanting their child to do well* during the intensive program and other therapies. The medical system was not easy to negotiate and making decisions regarding the child could be difficult. *"It is always very hard. It is stressful and exhausting."*

Because of the many challenges families face having a child with a disability, *networking is critical* to caregivers. Meeting another family *in the same boat* can relieve some of the pressures families face. Being able to talk frankly and honestly with other parents who do *"not give me that look" but who understand* the daily struggle of having a child with special needs was helpful. Many caregivers felt isolated and sharing with another family so *"you don't feel so alone"* was therapeutic. The intensive program provided families opportunities for networking with other families. *"The talking to other moms I think has been helpful to me."* Social opportunities were also available for the children participating in the program; "*his buddy-(they) played together."*

Caregivers attributed the unique qualities in therapists working at the intensive program as critical to its success. Parents believed the therapists cared about their children and were sincere in *wanting to help them*. The therapists wanted to assist so the "*kids succeed in* *everything they can."* Families felt it was important to have a professional treating their child who listened and were *"passionate about" their jobs. "Expertise of the professional"* was valued and caregivers expressed the importance of the therapists *possessing teaching skills* so caregivers could be taught how to effectively help their children. *Mutual respect* of both therapists and caregivers were imperative for effective communication. Caregivers highly valued therapists who displayed "*caring and sympathetic" qualities* while connecting with their children. It was important to caregivers that their children were "pushed" in therapy with therapists *treating on the edge* but also reading the child's cues appropriately while adding an aspect of fun.

The intensive program provided an alternative to traditional therapy. *"It's more aggressive-it's more focused on the goal"*, and because the caregivers are present for the majority of the sessions, the educational aspect of the program was significant. Home programs were provided with carry-over expected. Despite the logical challenges, caregivers considered the intensive program a *"wonderful experience."* Assisting their children to be as independent as possible was a priority to caregivers. The intensive program assisted with functional independence and *provided hope:* "*a positive experience and I would recommend it to anyone."*

Conceptual Model

A conceptual model was developed from the intensive program experiences of the caregivers of the children participating in the program (Figure 4.4). The child is represented in the middle as the primary benefactor of the intensive intervention. The family is in the adjacent concentric circle illustrating their importance for the success of the intensive program. The next concentric ring contains optimal therapeutic conditions revealed by caregiver interviews. The outer ring represents both positive (on the right) and negative (on the left) variables affecting intensive intervention. Many variables are interactive and displayed by two-way arrows (e.g. the home program empowers parents and can provide hope for the future).

Summary

Results from the study were presented and descriptions of caregiver and children participants were provided. Child participants demonstrated statistically significant improved scores on the GAS and COPM pre-to post-intervention with the NDT intensive program. Interview data from 13 caregivers were analyzed using a phenomenological approach with verbatim examples described. Seven themes were identified as critical to their children's therapy programs: 1. Positive effects were seen with increased intensity; 2. Expert, compassionate therapists were valued; 3. Team collaboration was vital; 4. Objective, realistic goals were required; 5. Home programs with teaching were needed; 6. Funding and scheduling were challenging; and 7. Children and their families had individualized needs. Caregivers valued the intense format of the NDT program. Finally, a conceptual model illustrated caregiver perceptions from the intensive NDT program.

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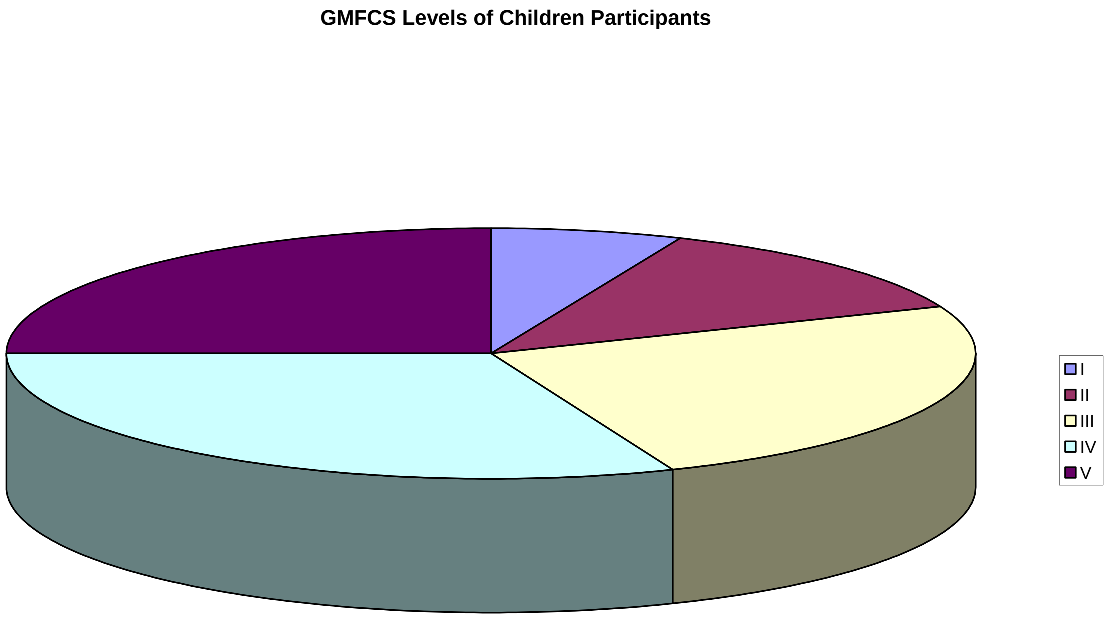

Figure 4.1 GMFCS Levels of Children Participants

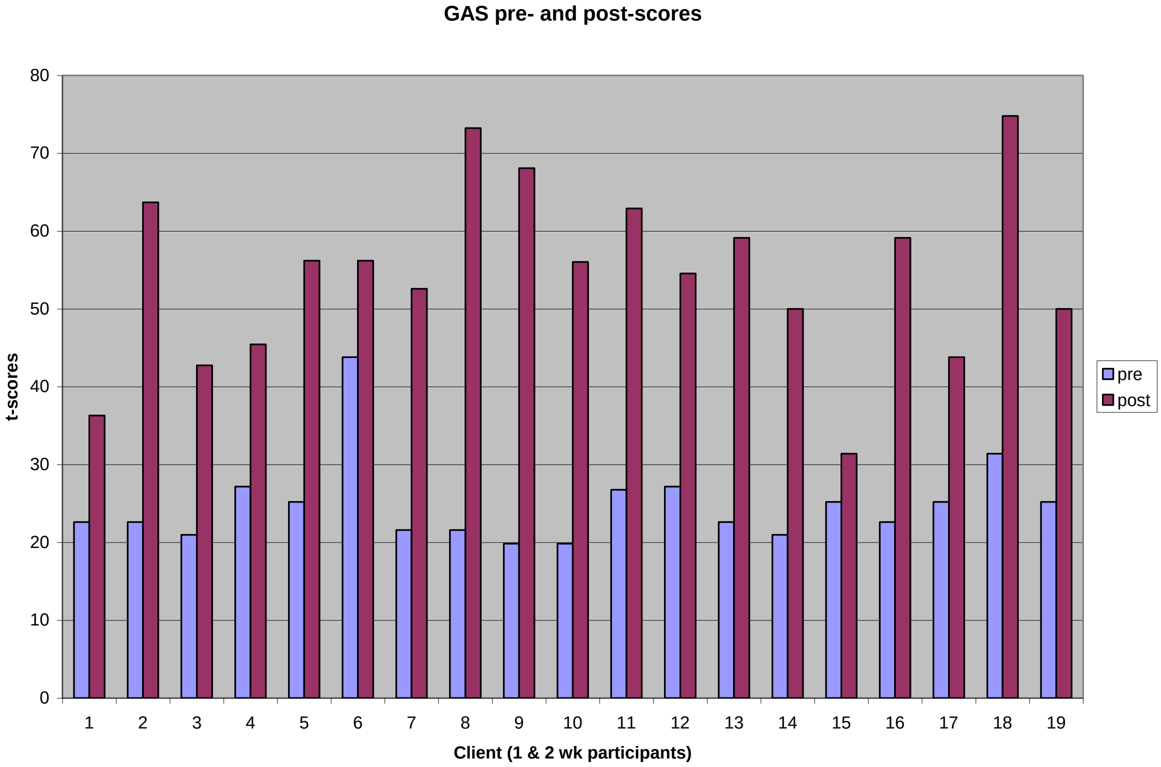

Figure 4.2: GAS Scores Pre- and Post-Intervention

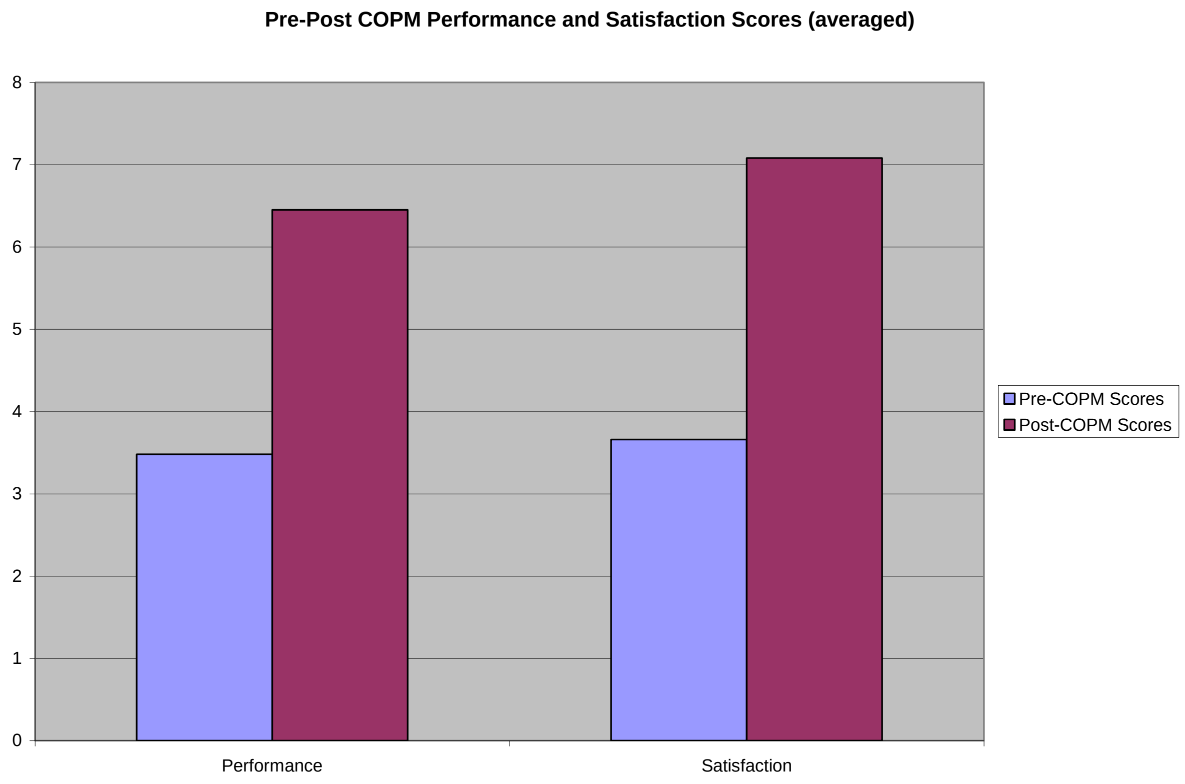

Figure 4.3 Mean COPM Scores (Performance/Satisfaction) Pre-Post Intervention

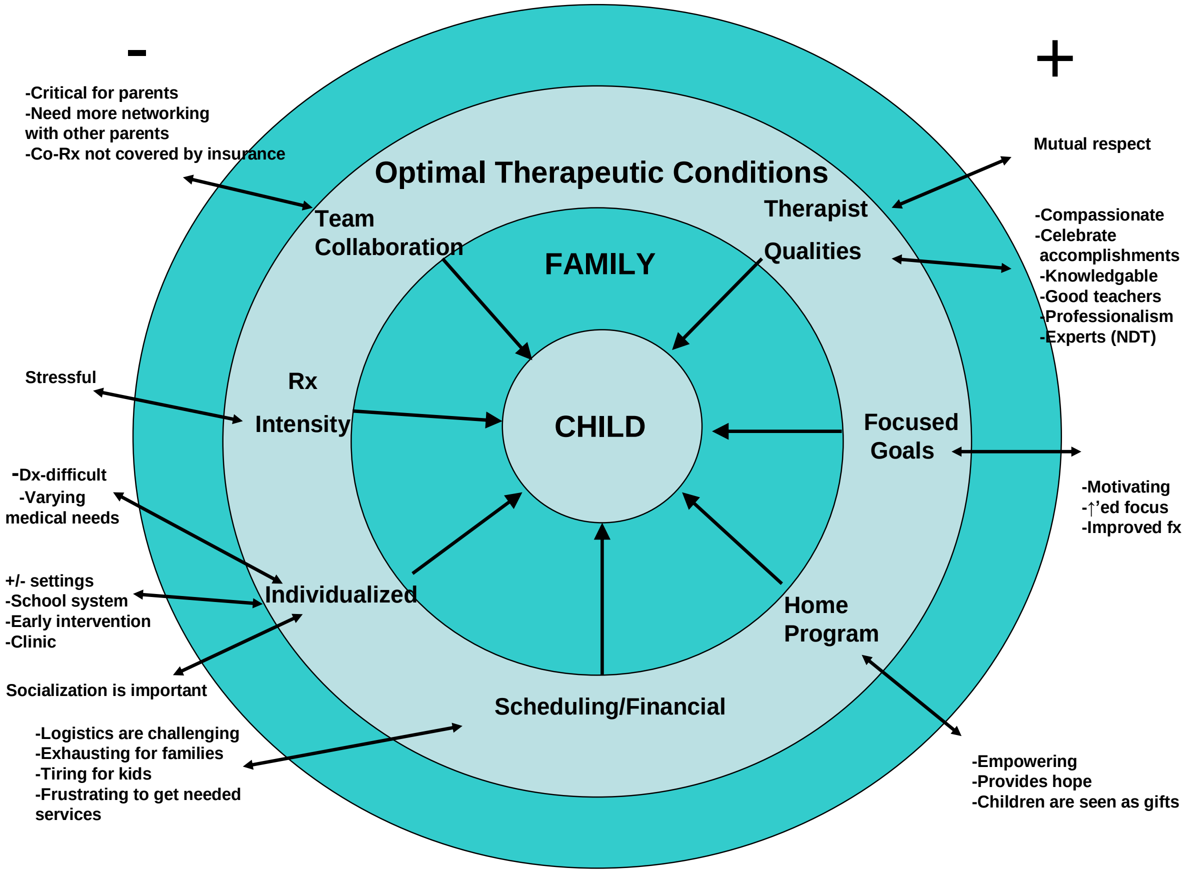

Figure 4.4 Conceptual Model of the Perception of Caregivers in their Child's Participation in NDT Intensive Program

Table 4.1 Child Demographic Characteristics (*11, 13 and 15 participated in both the July and October intensive sessions)

Child #	Gender	Age at time of data collection (yrs:mths)	GMFCS Level I	II	III	IV	V
1	M	16:3			X		
2	M	2:11			X		
3	F	6:9				X	
4	F	2:2			X		
5	M	17:6					X
6	M	6:6				X	
7	M	5:10	X				
8	F	1:11				X	
9	M	3:6			X		
10	M	4:4		X			
*11	F	2:2				X	
12	M	12:3					X
*13	F	2:5		X			
14	M	2:6				X	
*15	M	17:9					X
16	M	15:6					X

Table 4.2 Summary Demographic Information of Children Participants (n=16)

Variable	Summary Data
Age	
Mean Age	7 years 5 months
Gender	
Male	11
Female	5
Ethnicity	
Caucasian	13
African-American	0
Hispanic	1
Asian	1
Other ethnic group	1
GMFCS Level	
I	1
II	2
III	4
IV	5
V	4

Table 4.3: Caregiver Demographics Characteristics

Participant #	Relationship to Child	Child's Age (yrs:mths)	GMFCS Level of Child
1	Mother	16:3	III
2	Mother	2:11	III
3	Mother	6:9	IV
4	Mother	2:2	III
5	Mother	17:6	V
6	Mother	6:6	IV
7	Grandmother	5:10	I
8	Mother	1:11	IV
9	Mother	3:6	III
10	Mother	4:4	II
11	Mother	2:2	IV
12	Mother	12:3	V
13	Mother	2:5	II
14	Mother	2:6	IV
15	Mother	17:9	V
16	Mother	15:6	V

Table 4.4: Pre- and Post-Test Scores using GAS and COPM

Outcome Measure	Statistical Significance
GAS	P<.001
COPM	P<.001

Table 4.5 Pre- and Post-GAS Scores with T-Score Conversion (T-score conversion from Table A.2-A.6 in Kiresuk et al.[4])

Child	# of Goals	Pre-GAS	Average scale score	T-score		Post-GAS	Average scale score	T-score
CO1	3	-6	-2.00	22.62		-3	-1.00	36.31
CO2	3	-6	-2.00	22.62		3	+1.00	63.69
CO3	4	-8	-2.00	20.98		-2	-0.50	42.75
CO4	3	-5	-1.67	27.18		-1	-0.33	45.44
CO5 wk1	2	-4	-2.00	25.19		1	+0.50	56.21
CO5 wk2	2	-1	-0.50	43.79		1	+0.50	56.21
CO6 wk1	6	-11	-1.83	21.60		1	+0.17	52.58
CO6 wk2	6	-11	-1.83	21.60		9	+1.50	73.24
CO7	5	-10	-2.00	19.85		6	+1.20	68.09
CO8 wk1	5	-10	-2.00	19.85		2	+0.40	56.03
CO8 wk2	6	-9	-1.50	26.76		5	+0.83	62.91
CO9	3	-5	-1.67	27.18		1	+0.33	54.56
C10	3	-6	-2.00	22.62		2	+0.67	59.13
C11	4	-8	-2.00	20.98		0	0	50.00
C12	2	-4	-2.00	25.19		-3	-1.50	31.39
C13	3	-6	-2.00	22.62		2	+0.67	59.13
C14	2	-4	-2.00	25.19		-1	-0.50	43.79
C15	2	-3	-1.50	31.39		4	+2.00	74.81
C16	2	-4	-2.00	25.19		0	0	50.00

Table 4.6 Pre- and Post-COPM Scores

Week 1 or 2, Child # and Discipline Goals	Pre-Perf	Post-Perf	Pre-Satis	Post-Satis
CO1-PT1	2	8	3	9
CO1-OT1	2	9	2	9
CO1-OT2	2	9	2	9
CO2-PT1	4	6	2	5
CO2-PT2	6	7	5	7
CO2-OT1	4	6	6	7
CO3-PT1	5	5	5	5
CO3-PT2	1	3	1	3
CO3-OT1	2	3	1	3
CO3-OT2	1	5	1	5
CO4-PT1	2	4	5	7
CO4-PT2	3	4	10	10
CO4-OT1	2	6	3	8
1CO5-PT1	7	7	1	10
1CO5-OT1	4	8	1	10
2CO5-PT1	7	8	10	10
2CO5-OT1	8	10	10	10
1CO6-PT1	3	6	4	8
1CO6-OT1	2	4	2	5
1CO6-OT2	4	7	4	7
1CO6-SLP1	3	4	3	4
1CO6-SLP-2	3	5	3	5
1CO6-SLP-3	6	9	6	9
2CO6-PT1	3	7	3	8
2CO6-OT1	4	8	4	8
2CO6-OT2	5	8	5	8
2CO6-SLP1	3	4	3	4
2CO6-SLP-2	4	4	4	4
2CO6-SLP-3	7	9	7	9
CO7-PT1	1	10	1	10
CO7-PT2	4	10	4	10
CO7-OT1	2	4	2	6
1CO8-PT1	4	5	4	4
1CO8-PT2	1	5	3	6
1CO8-OT1	3	6	3	6
1CO8-OT2	4	7	3	7
1CO8-OT3	2	5	2	5

Table 4.6 Table of Pre-Post COPM Scores (cont'd)

Child # and Discipline Goals	Pre-Perf	Post-Perf	Pre-Satis	Post-Satis
2CO8-PT1	3	5	3	5
2CO8-PT2	2	6	2	6
2CO8-OT1	5	7	5	8
2CO8-OT2	5	8	5	8
2CO8-OT3	3	7	3	7
2CO8-SLP1	7	8	6	8
CO9-PT1	1	9	2	10
CO9-OT1	1	8	1	10
CO9-OT2	2	6	1	6
C10-PT1	2	9	3	9
C10-OT1	4	6	3	6
C10-SLP1	3	9	2	7
C11-PT1	3	5	2	7
C11-OT1	3	5	2	5
C11-OT2	2	7	2	7
C11-SLP1	4	8	4	8
C12-PT1	7	*	4	*
C12-OT1	2	*	4	*
C13-PT1	3	8	6	9
C13-PT2	3	6	6	7
C13-SLP1	1	8	1	10
C14-PT1	2	7	2	7
C14-OT1	3	6	6	7
C15-PT1	7	8	6	10
C15-SLP1	8	8	7	10
C16-PT1	4	6	5	8
C16-OT1	3	8	3	8
Totals	223	413	234	453
Averaged scores	3.48	6.45	3.66	7.08

* post-testing not performed due to family emergency

Table 4.7: Study Quantitative Data Results for Individual Child Participants (Intensive Program-7/10 and 10/10)

1st Intensive Program session in July (only 3 children were 2 weeks: CO 5, 6 & 8)

CO1: GMFCS Level III (1 week only)

Goals	Pre-GAS	Post-GAS	Pre-COPM: Imp.	Pre-COPM: Perf.	Pre-COPM: Satis.	Post-COPM: Imp.	Post-COPM: Perf.	Post-COPM: Satis.
PT: 1. sit to stand	-2	+1	9	2	3	10	8	9
OT: 1. pulling up sweatpants	-2	+2	9	2	2	9	9	9
OT: 2. lift foot to place on sweatpants	-2	0	9	2	2	9	9	9

Total Goals=3

Goals: (Expected level of outcome-0)
PT: (1 goal) 1. Pt. will transfer from sit to stand from an elevated bench symmetrically over bilateral L.E. with support of bilateral U.E. on a walker placed in front of him.
OT: (2 goals) 1. Pt will pull up pants (donning sweatpants) from thigh to hip and clearing bottom with L hand while supporting self with R UE in standing at walker.
OT: 2. While bench sitting to take shoes and socks off, Pt. will lift L foot at floor 5 in. and maintain sitting balance with 90/90/90 posture to initiate sweatpants placement over foot.

CO2: GMFCS Level III (1 week only)

Goals	Pre-GAS	Post-GAS	Pre-COPM: Imp.	Pre-COPM: Perf.	Pre-COPM: Satis.	Post-COPM: Imp.	Post-COPM: Perf.	Post-COPM: Satis.
PT: 1. walk	-2	0	10	4	2	10	6	5
PT: 2 Stand and play	-2	+1	10	6	5	10	7	7
OT: 1. stand and dressing	-2	+2	10	4	6	10	6	7

Total Goals=3

Goals: (Expected level of outcome-0)
PT: (2 goals) 1. Using posterior walker, Pt will maintain Independent wt. bearing through arms and take 5 3 inch steps with no crossing of LEs and with assistance at knees.
PT: 2. Pt. will stand and play maintaining an erect posture while facilitated at hips and knees and playing with toys for 30 seconds.

OT: 1. Pt. will actively use one hand to hold and weight bear forward on supportive surface at shoulder height while mom pulls up loose pants.

CO3: GMFCS Level IV (1 week only)

Goals	Pre-GAS	Post-GAS	Pre-COPM: Imp.	Pre-COPM: Perf.	Pre-COPM: Satis.	Post-COPM: Imp.	Post-COPM: Perf.	Post-COPM: Satis.
PT: 1. walk across the room	-2	-1	10	5	5	10	5	5
PT: 2 Transition from sit to stand to sit	-2	0	10	1	1	10	3	3
OT: 1. self feeding with spoon	-2	-1	10	2	1	10	3	3
OT: 2. pouring a drink	-2	0	10	1	1	10	5	5

Total Goals=4

Goals: (Expected level of outcome-0)
PT: (2 goals) PT: 1. Pt. will walk with her walker independently 10 feet in 45 seconds leading with a step.
PT: 2. Pt. will transition sit to standing and then to sitting at a 45 degree angle support to trunk and support on hands.
OT: (2 goals) OT: 1. With R hand, pt. will be able to orient spoon to mouth to take 3-5 bites of food without spilling with 3 different food items of varying consistency (e.g. oatmeal, yogurt, rice).
OT: 2. Pt will stabilize a narrow cup that’s placed in hand on table surface providing forearm support and pour self a drink form a greater than 4 oz. container without spilling with verbal cues.

CO4: GMFCS Level III (1 week only)

Goals	Pre-GAS	Post-GAS	Pre-COPM: Imp.	Pre-COPM: Perf.	Pre-COPM: Satis.	Post-COPM: Imp.	Post-COPM: Perf.	Post-COPM: Satis.
PT: 1. stand	-2	-1	10	2	5	10	4	7
PT: 2. walk	-2	-2	8	3	10	8	4	10
OT: 1. input to tongue	-1	+2	10	2	3	10	6	8

Total Goals=3
Goals: (Expected level of outcome-0)

PT: (2 goals) 1. Pt. will stand with feet in place for 30 seconds maintaining balance while reaching for toys with UEs.
PT: 2. Pt. will take 6 steps independently with trunk aligned over hips and stop without falling.
OT: 1. Pt. will tolerate proprioceptive input on base of tongue for 8 seconds.

CO5: GMFCS Level V (2 weeks)
1st week

Goals	Pre-GAS	Post-GAS	Pre-COPM: Imp.	Pre-COPM: Perf.	Pre-COPM: Satis.	Post-COPM: Imp.	Post-COPM: Perf.	Post-COPM: Satis.
PT: 1. standing transfer	-2	0	10	7	1	10	7	10
OT: 1. eating	-2	+1	10	4	1	10	8	10

Total Goals=2
2nd week

Goals	Pre-GAS	Post-GAS	Pre-COPM: Imp.	Pre-COPM: Perf.	Pre-COPM: Satis.	Post-COPM: Imp.	Post-COPM: Perf.	Post-COPM: Satis.
PT: 1. transfers in standing	0	+1	10	7	10	10	8	10
OT: 1. eating	-1	0	10	8	10	10	10	10

Total Goals=2

Week 1 Goals: (Expected level of outcome-0)
PT: (1 goal) 1. Pt. will shift weight onto L LE and maintain knee extended for 5 seconds with maximal assistance of 1 for transfers into stander.
OT: 1. (1 goal) Pt. will coordinate oral motor movements to transfer food presented via a spoon for a coordinated swallow 5 out of 10 presentations.

Week 2 Goals: (Expected level of outcome-0)
PT: (1 goal) 1. Pt. will stand on one leg shifting weight onto left LE maintaining knee extension for 5 seconds with assistance of 1 while lifting other leg to step/place it on stander footplate.
OT: 1. (1 goal) Pt. will coordinate oral motor movements to transfer food presented via a spoon for a coordinated swallow 7 out of 10 presentations.

Note regarding feeding goal:
(by end of 1st week was able to do 5/7 presentations. Began with goal of +1 (7/10) for 2nd week but on 1st day- unable to achieve what was achieved the end of last week- so started at the -1 level: 3/10 presentations.

CO6: GMFCS Level IV (2 weeks)
1st week

Goals	Pre-GAS	Post-GAS	Pre-COPM: Imp.	Pre-COPM: Perf.	Pre-COPM: Satis.	Post-COPM: Imp.	Post-COPM: Perf.	Post-COPM: Satis.
PT: 1. independent stance with quad cane	-2	+1	9	3	4	9	6	8
OT: 1. left release	-2	0	7	2	2	7	4	5
OT: 2. name stamping	-2	0	8	4	4	8	7	7
SLP: 1. General interaction	-2	-1	9	3	3	9	4	4
SLP: 2. Turn taking with peer	-2	-1	9	3	3	9	5	5
SLP: 3. Visual schedule	-1	+2	9	6	6	9	9	9

Total Goals=6

2nd week

Goals	Pre-GAS	Post-GAS	Pre-COPM: Imp.	Pre-COPM: Perf.	Pre-COPM: Satis.	Post-COPM: Imp.	Post-COPM: Perf.	Post-COPM: Satis.
PT: 1. independent stance with quad cane	-2	+2	9	3	3	9	7	8
OT: 1. left release	-2	+2	8	4	4	8	8	8
OT: 2. name stamping	-2	+2	8	5	5	8	8	8
SLP: 1. General interaction	-2	+1	9	3	3	9	4	4
SLP: 2. Turn taking-peer	-2	0	9	4	4	9	4	4
SLP: 3. Visual schedule	-1	+2	9	7	7	9	9	9

Total Goals=6

Week 1

Goals: (Expected level of outcome-0)

PT: 1. Pt. will stand independently with quad cane in right UE and maintain pushing down into the floor to balance independently for 10 seconds.

OT: (2 goals) OT 1. Pt. will release item with left hand with assist to stabilize wrist and forearm by 3rd attempt.

OT: 2. Pt. will utilize left hand to stamp name within borders while sustaining force of pushing for count of five with verbal cueing and arm guidance.

SLP: (3 goals) SLP 1. Pt. will use augmentative communication device to initiate interaction with peer on 3 occasions, requiring minimal prompting to initiate the interactions during the session.

SLP: 2. Pt. will use augmentative communication device for 6 turn taking interactions with peer during game when provided cues during session.

SLP: 3. Pt. will follow visual schedule participating in each activity up to 6 pictures attending to activity for 15 minutes until picture is removed and next picture activity is presented.

Week 2

Goals: (Expected level of outcome-0)

PT: 1. PT: 1. Pt. will stand independently with quad cane in right UE and maintain pushing down into the floor to balance independently for 20 seconds.

OT: (2 goals) OT 1. Pt. will release item with left hand with assist to stabilize wrist and forearm by 2nd attempt 3/5 trials.

OT: 2. Pt. will utilize left hand to stamp name within borders while sustaining force of pushing for count of five with verbal cueing and arm guidance.

SLP: (3 goals) SLP 1. Pt. will use augmentative communication device to initiate interaction with peer on 3 occasions, requiring minimal prompting to initiate the interactions during the session.

SLP: 2. Pt. will use augmentative communication device for 6 turn taking interactions with peer during game when provided cues during session.

SLP: 3. Pt. will follow visual schedule participating in each activity up to 6 pictures attending to activity for 15 minutes until picture is removed and next picture activity is presented.

Note: PT goal- Pt was tired after weekend (went to wedding out of town) and did not stand independently with quad cane as he was able to do at end of last week.

CO7: GMFCS Level I (1 week only)

Goals	Pre-GAS	Post-GAS	Pre-COPM: Imp.	Pre-COPM: Perf.	Pre-COPM: Satis.	Post-COPM: Imp.	Post-COPM: Perf.	Post-COPM: Satis.
PT: 1. bike riding	-2	+2	9	1	1	9	10	10
PT: 2. Stepping up (bus)	-2	+2	9	4	4	9	10	10
OT: 1. prehension	-2	-1	10	2	2	10	4	6
SLP: 1. hands on face	-2	+2						
SLP: 2. feelings	-2	+1						

Total Goals=5 *note no COPM scoring was done by SLP because initially she was not sure if speech would be involved for entire scoring time

Goals: (Expected level of outcome-0)
PT: (2 goals) 1. Pt. will sit on bike with hands on handle bars with feet on pedals with front wheel stabilized by therapist and rock bike side to side.
PT: 2.Pt will independently step up 1 inch height without loss of balance 2 times in a session.
OT: 1. Pt. will hold an adaptive pencil with a tripod grasp to complete a 12 inch shape.
SLP: (2 goals) 1. Pt. will allow hands on his face for 10 seconds after first touching therapists face.
SLP: 2. Pt. will name pictures plus vocalize one sentence using target vocabulary.
CO8: GMFCS Level II (2 weeks)

1st week

Goals	Pre-GAS	Post-GAS	Pre-COPM: Imp.	Pre-COPM: Perf.	Pre-COPM: Satis.	Post-COPM: Imp.	Post-COPM: Perf.	Post-COPM: Satis.
PT: 1. all fours	-2	-1	10	4	4	10	5	4
PT: 2. stepping	-2	0	8	1	3	8	5	6
OT: 1. stabilize	-2	+1	8	3	3	8	6	6
OT: 2. pincer	-2	+2	8	4	3	8	7	7
OT: 3. release	-2	0	8	2	2	8	5	5

Total Goals=5

*2nd week

Goals	Pre-GAS	Post-GAS	Pre-COPM: Imp.	Pre-COPM: Perf.	Pre-COPM: Satis.	Post-COPM: Imp.	Post-COPM: Perf.	Post-COPM: Satis.
PT: 1. all fours	-1	-1	10	3	3	10	5	5
PT: 2. stepping	0	0	10	2	2	10	6	6
OT: 1. stabilize	-2	+2	8	5	5	9	7	8
OT: 2. pincer	-2	+2	8	5	5	8	8	8
OT: 3. release	-2	+2	9	3	3	9	7	7
*SLP: 1. lip closure	-2	0	9	7	6	10	8	8

Total Goals=6
*SLP provided 2nd week only

Week 1
Goals: (Expected level of outcome-0)
PT: (2 goals) PT: 1. Pt will independently move sitting to all fours at least twice during a session.
PT: 2. Pt. will stand unsupported at chest high furniture and lift then replace each foot.
OT: (3 goals) OT: 1. Pt will stabilize 1 hand to hold/stabilize self and other UE to engage in play for 15 seconds with assist to initiate 1/3 times.
OT: 2. Pt. will utilize pincer grasp to pick up cereal with right hand on 1st attempt 2 times during session.
OT: 3. Pt will release item into container with assist to stabilize wrist/ forearm by 3rd attempt.

Week 2
Goals: (Expected level of outcome-0)
PT: (2 goals) PT: 1. Pt. will independently move sitting to all fours at least twice during a session.
PT: 2. Pt. will cruise in one direction at least one step.
OT: (3 goals) OT: 1. Pt. will stabilize 1 hand to hold/stabilize self and other UE to engage in play for 15 seconds with assist to initiate 1/3 times.
OT: 2. Pt. will utilize pincer grasp to pick up cereal with right hand on 1st attempt 2 times during session.
OT: 3. Pt will release item into container with assist to stabilize wrist/ forearm by 3rd attempt.
SLP: 1. Pt will demonstrate active lip closure with suctioning during swallowing on 3 out of 5 trials and on at least two different occasions when given liquids form an open cup with oral support provided.

CO9: GMFCS Level III
1st week

Goals	Pre-GAS	Post-GAS	Pre-COPM: Imp.	Pre-COPM: Perf.	Pre-COPM: Satis.	Post-COPM: Imp.	Post-COPM: Perf.	Post-COPM: Satis.
PT: 1. Indep. stance	-2	+1	10	1	2	10	9	10
OT: 1. dressing	-2	0	8	1	1	10	8	10
OT: 2. feeding	-1	0	10	2	1	10	6	6

Total Goals=3

Week 1
Goals: (Expected level of outcome-0)
PT: PT: 1. Pt. will stand independently with back up against the wall and actively weight shift forward (anteriorly) 1x off the wall while maintaining balance to pop a bubble placed forward at eye level.
OT: (2 goals) 1. While sitting on a bench placed against the wall, Pt. will don a loose pull-over shirt with set-up assistance for initiation, 2/3 trials.
OT: 2. Pt. will tolerate taking 3 tastes of a preferred food via the spoon.

2nd Intensive Program session in October

C10: GMFCS Level II

Goals	Pre-GAS	Post-GAS	Pre-COPM: Imp.	Pre-COPM: Perf.	Pre-COPM: Satis.	Post-COPM: Imp.	Post-COPM: Perf.	Post-COPM: Satis.
PT: 1. walk 20◦ incline	-2	+1	9	2	3	9	9	9
OT: 1. dressing	-2	-1	10	4	3	10	6	6
SLP: 1. chewing	-2	+2	8	3	2	10	9	7

Total Goals=3

Goals: (Expected level of outcome-0)
PT: 1. Pt. will independently ambulate facing forward on a 20 % graded grassy surface incline for 5 feet without stopping/avoidance or loss of balance 5x by the end of the week.
OT: 1. Pt. will be able to grasp pants or underwear with each hand and push them down to mid thigh with 3 or less verbal cues 3x by the end of the week.
SLP: 1. Pt. will increase his ability to chew on the right side of his mouth by demonstrating repetitive biting/chewing 3 times before swallowing resistant solid food during therapy session with neutral placement and oral control provided by 10/29/10.

C11: GMFCS Level IV

Goals	Pre-GAS	Post-GAS	Pre-COPM: Imp.	Pre-COPM: Perf.	Pre-COPM: Satis.	Post-COPM: Imp.	Post-COPM: Perf.	Post-COPM: Satis.
PT: 1. walk	-2	-1	10	3	2	10	5	7
OT: 1. dressing upper body	-2	-1	7	3	2	8	5	5
OT: 2. dressing lower body	-2	0	7	2	2	8	7	7
SLP: 1. swallowing/secretion management	-2	+2	9	4	4	9	8	8

Total Goals=4

Goals: (Expected level of outcome-0)
PT: 1. Pt. will ambulate 35 feet forward with 2 hand-held assist by the end of the week.
OT: 1. Pt. will independently don shirt overhead using both hands to put shirt on head and pull it down and place arms into sleeves once hands are oriented to holes while in independent bench sit.
OT: 2. Pt. will lift each leg in anticipation for lower body dressing while in bench sit, independently laterally weight shifting (flexion with rotation) with a downward visual gaze 2/4 times.
SLP: 1. Pt. will initiate secretion swallowing on 3 of 5 trials when tactile/visual/auditory/proprioceptive cue of labial compression/suction and input into suprahyoid musculature is provided by end of the week.

C12: GMFCS Level V

Goals	Pre-GAS	Post-GAS	Pre-COPM: Imp.	Pre-COPM: Perf.	Pre-COPM: Satis.	Post-COPM: Imp.	Post-COPM: Perf.	Post-COPM: Satis.
PT: 1. transition-sit-stance	-2	-2	10	7	4	10	*	*
OT: 1. switch activation	-2	-1	10	2	4	10	*	*

Total Goals=2
* unable to obtain post-intervention COPM with parent due to medical emergency in family

Goals: (Expected level of outcome-0)
PT: 1. Pt. will independently ambulate facing forward on a 20 % graded grassy surface incline for 5 feet without stopping/avoidance or loss of balance 5x by the end of the week.
OT: 1. Pt. will be able to activate a toggle switch with his left elbow 7/10 attempts within 15 sec. with each attempt to lead to ability to independent engage environmental control switch.

C13: GMFCS Level II

Goals	Pre-GAS	Post-GAS	Pre-COPM: Imp.	Pre-COPM: Perf.	Pre-COPM: Satis.	Post-COPM: Imp.	Post-COPM: Perf.	Post-COPM: Satis.
PT: 1. Step with visual focus	-2	0	10	3	6	10	8	9
PT: 2. descend stairs	-2	0	10	3	6	10	6	7
SLP: 1. communication	-2	+2	10	1	1	10	8	10

Total Goals=3

Goals: (Expected level of outcome-0)
PT: 1. Pt. will visually focus with eyes and step up small height (2 inches) with auditory cueing toward step 1x without loss of balance by the end of the week.
PT: 2. Pt. will descend 2 stairs safely feeling with her foot the step below before descending seen by the end of the week.
SLP: 1. Pt. will visually attend to simple PEC (pictorial communication board) and indicate at least 2 wants by the end of the week.

C14: GMFCS Level IV

Goals	Pre-GAS	Post-GAS	Pre-COPM: Imp.	Pre-COPM: Perf.	Pre-COPM: Satis.	Post-COPM: Imp.	Post-COPM: Perf.	Post-COPM: Satis.
PT: 1.take steps	-2	-1	10	2	2	10	7	7
OT: 1. Transition sit to supine	-2	0	10	3	6	10	6	7

Total Goals=2

Goals: (Expected level of outcome-0)
PT: 1. Pt will be able to take steps for 20 feet with one hand held without need to support trunk with therapist initiating hand hold by the end of the week.
OT: 1. Pt. will transition from sitting to supine given a lateral weight shift, placing his hand to the surface by the end of the week.

C15: GMFCS Level V

Goals	Pre-GAS	Post-GAS	Pre-COPM: Imp.	Pre-COPM: Perf.	Pre-COPM: Satis.	Post-COPM: Imp.	Post-COPM: Perf.	Post-COPM: Satis.
PT: 1. walking	-2	+2	10	7	6	10	8	10
SLP: 1. feeding	-1	+2	10	8	7	10	8	10

Total Goals=2

Goals: (Expected level of outcome-0)
PT: 1. Pt will ambulate 100 feet with moderate assistance with tactile cues of lower extremity by the end of the week.
SLP: 1. Pt. will participate in successful spoon feedings accepting at least 8 presentations with a coordinated oral and pharyngeal phase of the swallow by the end of the week.

C16: GMFCS Level V

Goals	Pre-GAS	Post-GAS	Pre-COPM: Imp.	Pre-COPM: Perf.	Pre-COPM: Satis.	Post-COPM: Imp.	Post-COPM: Perf.	Post-COPM: Satis.
PT: 1. Pivot transfer	-2	0	10	4	5	10	6	8
OT: 1. toileting	-2	0	9	3	3	10	8	8

Total Goals=2

Goals: (Expected level of outcome-0)
PT; 1. Pt will be able to transfer with the assistance of one with pt actively participating by pushing into the surface with lower extremities and feet to pivot transfer without mom needing to lift by the end of the week.
OT: 1. Pt. will stand with assistance as needed to grasp restroom grab bars independently for 10 seconds, 2/3 trials by the end of the week.

Table 4.8: Site Visit Quantitative Data Results (not included in study findings)

Child A: Pre-and Post-Testing using GAS and COPM

Goal Attainment Scale (GAS)

	Pre-test	**Post-test**
Goal #1 Aug com.	**-2**	**+2**
Goal #2 Sitting	**-2**	**+2**
Goal #3 Stance	**-2**	**+2**

Canadian Occupational Performance Measure (COPM)

	Time 1			**Time 2**	
Problems	**Importance**	**Performance**	**Satisfaction**	**Performance**	**Satisfaction**
1. Aug com.	**10**	**1**	**1**	**5**	**8**
2. Sitting	**10**	**3**	**3**	**7**	**7**
3. Stance	**10**	**4**	**4**	**8**	**8**

Table 4.9 Qualitative Study Results-Clustering of Invariant Constituents of Caregivers' Experiences into Themes

Theme	Invariant Constituents
1. Effects of increased intensity of intervention were viewed as highly beneficial by caregivers.	• Loved intensive and felt like it was what my child • needed • Specific times of increased therapy recommended
2. Unique qualities of the therapists such as expertise and compassion were important to the caregivers.	• Experts in field and knowledgeable • NDT handling expertise • Mutual respect • Celebrate accomplishments with us • Flexible and compassionate • It is important to communicate well • Warm people and nice atmosphere • Liked new set of eyes and fresh perspective • I'm not a therapist
3. Team collaboration as part of the intensive program was highly valued by the caregivers.	• Liked team of OT, PT and SLP working together • Liked working and ideas for other "regular" home therapists
4. The focus of specific time-intensive goals written to improve functional abilities was meaningful to caregivers.	• Caregivers liked giving input on goals • Setting specific goals for weeks increased focus of team • Having specific goals helped setting realistic outcomes • Working on building foundational skills first helped with goals and carry-over
5. Specific home programming with specific suggestions for carry-over when not in therapy was viewed as beneficial to caregivers.	• Liked home program with pictures and Power point with suggestions • Important for therapists to explain what they are doing with therapy suggestions for home • Home program helped carry-over for day to day activities
6. Scheduling the intensive program with families and insurance coverage for the program could be problematic.	• Intensive was intense and required specific scheduling for families including changing routines-(this could be tough and stressful) • Financial and insurance coverage for needed regular therapies and for intensive therapy is difficult
7. Each child is unique with different strengths and difficulties.	• Kids do things on their own schedule sometimes • Children with disabilities present unique care giving challenges • Some kids do better in clinic vs. home setting • Social interactions are important for families

Table 4.10 Qualitative Study Results-Themes and Textural Statements

Theme 1. Effects of increased intensity of intervention were viewed as highly beneficial by caregivers.
Statements from caregivers illustrating positive effects and important benefits of the intensive program
Caregivers expressed specific intensive program benefits compared to more traditional therapy
Statements from caregivers illustrating positive effects and benefits of the intensive program for both caregiver and child
Statements from caregivers suggesting intensive program improved sleep of child
Provided hope for caregivers with expectations exceeded
Theme 2. Unique qualities of the therapists such as expertise, being a good teacher, having compassion, good listening skills and providing hope were essential keys to the success of the intensive program for caregivers.
Therapists seen as experts with professionalism in the pediatric field
Specifically, NDT training of the therapists was highly valued by many caregivers
A few caregivers shared they only have NDT-trained therapists treat their children
The sharing of knowledge and verification of information is empowering to caregivers providing hope and motivation simultaneously
Unique personal qualities of the therapists participating in the NDT intensive program contributed to the success of the program; The therapists were passionate about what they do
The therapists were connected with the children to gain their trust--displaying qualities of patience, listening and reading cues well
The therapists demonstrated positive attitudes and celebrated successes instilling hope and higher expectations for the children and their caregivers
The value of the therapists taking time to listen and gain trust, meeting the child based on developmental status, and treating the entire family with respect is very important for an effective therapist/client/caregiver relationship
Statements from caregivers supporting the comfortable, relaxed environment and flexibility
Statements from caregivers supporting the value of having new therapists at the intensive program providing a fresh perspective with their child
Fresh perspective with trying equipment is helpful to caregivers
Theme 3. Team collaboration as part of the intensive program was highly valued by the caregivers.
Statements from caregivers illustrating the important value of team collaboration during the intensive program
Collaboration of the three different disciplines: PT, OT and SLP

Statements by caregivers suggesting collaboration improves progress toward goal attainment for the child
With some children it is helpful to have more hands available for treating them effectively
Statements that suggest knowledge was gained by caregiver as a result of exposure to "team concept"; amazing results with combining knowledge and collaboration
The value of collaboration for sharing information with others including outside therapists, assistants, teachers, and family members
Theme 4. Collaboratively setting objective, realistic goals to improve functional abilities of the child was an effective strategy for goal attainment and highly valued by caregivers.
Statements by caregivers supporting the importance of planning and having focused goals set collaboratively
Statements supporting the importance of realistic, objective goals to track progress of child and providing motivation for caregiver
Statements supporting specific improvement or progress on functional goals and skills were important to caregivers
Statements supporting specific improvement or progress on components of movement including different system impairments and foundational skills are important to caregivers
Statements supporting goal attainment provides hope for caregivers
Theme 5. Home programs with teaching intervention techniques were viewed as essential for carry-over in the home and other settings.
Statements from caregivers supporting positive views of home program and the importance of using it for carry-over at home for improved function
Statements supporting being able to use the home program for educating family members and others involved in the care of the child
Statements supporting being able to use the home program for educating other professionals involved in the care of the child
Caregivers appreciated having a sounding board for carry-over at home
Theme 6. Roadblocks caregivers encountered in the delivery of therapy services with insurance coverage and scheduling impacted their children's participation in the intensive program.
Statements supporting financial constraints (private insurance: federally funding) preventing participation despite caregivers' perspective that the intensive program is beneficial for their children
Statements illustrating feelings of frustration and worry from caregivers from inability to afford therapy services the caregivers feel the child needs
Statements from caregivers demonstrating a desire for changes to support the delivery of therapy services like the intensive program for their children
Statements from caregivers supporting the significant time commitment for the

intensive program; the tiring/exhausting effects for kids and exhausting/stressful effects on parents
Caregivers' statements supporting sacrifices including long drives and hotel stays for their child to participate in the intensive program
Caregivers' statements supporting logistical planning and advanced scheduling is required and can be challenging
Theme 7. There's no cookbook answer; each child and family is unique with different strengths and difficulties. Intervention must be based on individual needs and abilities of the child with the disability and family.
Parents have hope and realize their children are unique
Validating child for who he/she is and where they are developmentally- children are gifts and caregivers feel blessed
Statements supporting caregivers are strong advocates for their children
Statements from caregivers illustrating the importance of increased social interactions for their children
Statements supporting it is sometimes exhausting for parents advocating for their children with disabilities
Parents get tired of therapy
Specifically dealing with the medical diagnoses and disabilities of the child can be difficult for caregivers; they grieve about a future that will not be
Statements suggesting therapy can be stressful for caregiver
Statements supporting the need to recognize limitations of families and the children (including individual and contextual barriers)
Statements from caregivers supporting the value of networking and being with other caregivers of children with special needs (not feeling so alone)
Statements revealing caregivers opinions on therapy services for their child varying in different settings *a. Dissatisfaction of home (Early Intervention-EI) services compared to clinic visits* *b. Statements supporting dissatisfaction with School therapy*
Statements from caregivers supporting dissatisfaction of therapy due to limited services

CHAPTER V

Discussion, Summary and Conclusions

Discussion

This study provides evidence that a short-term intensive NDT program improved functional skills when a collaborative approach focused on realistic, quantitative goals of primary importance to children, caregivers, and therapists. Caregivers found intensive therapy to be beneficial with qualitative changes and positive outcomes achieved during an intensive program. Both the GAS and COPM were found to be effective tools for experienced NDT-trained clinicians to document quantitative changes in PT, OT and SLP goals. Although a small sample size was used for the quantitative data, statistically significant changes were found in functional skills. This study provides evidence to support NDT with an increased intensity for children with neuromotor disabilities for goal attainment and improving function. It also provides qualitative evidence supporting intensive NDT as a therapeutic intervention option valued by caregivers. In this study caregivers voiced opinions and shared perceptions and experiences regarding an intensive therapy option and how the intensive program met the needs of their family and child. A range of design and methodological factors contributed to the positive results of the study:

- A mixed method design combining both qualitative and quantitative data added rigor to the study.
- Children and adolescents with similar neuromotor impairments participated (homogeneous sampling e.g. delayed functional skills; majority of children functioning GMFCS Level III-V).

- A homogeneous group of parents of children with disabilities were interviewed (majority of parents were from Milwaukee area with similar availability of services).
- NDT intervention was provided according to a specific NDT protocol by certified/trained NDT therapists and instructors.
- Quantitative outcome measures were appropriate for measuring changes over time with interventions and all discipline goals were written using SMART guidelines.
- Intensive intervention was provided daily.
- Children served as their own controls in the quantitative aspect of the study with weekly pre-to post-intervention testing; maturation was not a factor in the changes in functional skill level.
- Documented changes in the children's performance on functional goals were parent-identified areas of greatest priority.
- Caregivers were present throughout the majority of the treatment sessions increasing validity of study for sharing perceptions of intensive program.
- Extensive home programming and education were provided for carry-over and further intervention.

Clinicians continue to seek appropriate, clinically relevant research to assist with decision-making for selecting optimal interventions for children. Intense activity-based practice and high intensity intervention have been found successful for improving function in individuals with neuromotor disabilities.[1-11]

Discrepancies in operational defined terms such as "Intensive" and "NDT" exist in the research and can be confusing. The term "intensive" can be used examining intervention frequency with a range from 1-5 times per week with varying treatment durations.[3, 4, 6, 8, 9, 12-15] In past research, operational definitions of NDT have been mistakenly focused on outdated principles such as "passive handling techniques."[16] For this reason, careful examination of NDT research is indicated to detect: 1. inaccurate and outdated information (e.g. studying changes in reflexes or tone) and 2. variations in specific frequency with "intensive" therapy relating to a range of therapy models (e.g. specific interventions such as direct, consultative, or adjunctive therapy, frequency of treatment sessions ranging from 1-5 times/month, or specific duration of therapy.)

The significant findings of this study are corroborated by 6 studies involving high intensity NDT intervention: Mayo,[12] Tsorlakis,[9] Trahan and Malouin[8, 17] Bierman,[4] and Arndt.[2] The high frequency of intervention (five days a week) and high total amounts of intervention (10-20 hours/week) in this study is similar to Storvold and Jahnsen,[3] Bierman[4] and Christy et al.[10]

In addition to high intensity intervention, this research supports the need for focused, objective goals for successful functional outcomes.[3, 4, 6, 18, 19] King, et al.[20] reported therapists continue to place less value on formal measurements, despite current emphasis on evidence-based practice and the importance of using appropriate, standardized outcome measures. Greater priorities were instead placed on establishing effective relationships. This study supported the importance of therapy relationships and highlighted insights by caregivers that team collaboration and unique qualities of therapists were valued. However, focused, realistic goals were also found to be motivating and highly valued by caregivers.

According to King et al.[20] barriers by therapists for using standardized outcome measures included time constraints, skill ineptness, and failure of appropriate measures to meet the needs of individuals' with disabilities. This study addressed these barriers by using two appropriate outcome measures, the GAS and COPM, found to be relatively easy to administer, required minimal skill training, and included both caregiver and therapy input for goal writing. Both outcomes also required minimal time for scoring and were appropriate for a clinical setting. An additional aspect found to be motivating and highly valued by the families was the collaborative goal setting by caregivers and therapists.

Collaboration among all therapists working with the child and family was an integral part of this research and found to be important to caregivers. Inadequate communication and team work may negatively affect progress toward functional outcomes. Writing collaborative outcomes with caregivers participating during therapy as integral team members had a large impact on the positive results in this study. Home programming with general information (e.g. equipment suggestions) and teaching handling techniques empowered parents in helping their children with disabilities after the intensive program finished. Consistent with positive findings in studies utilizing NDT experts,[2, 4, 21] caregivers in this study voiced strong positive opinions on therapists having expert NDT knowledge and teaching skills. Therapists' unique qualities such as being passionate about their work, having good listening skills and a positive attitude while gaining trust and rapport with the children were also appreciated by the caregivers.

Unique to this research was combining both quantitative and qualitative data in tandem; strengthening the overall results of the study.[22-24] None of the NDT studies reviewed by this researcher used a mixed method design. Only one study discovered by this researcher examined intensive intervention while using a qualitative approach.[10] Instead of NDT intervention, Christy et al.[10] used an intense model of PT consisting of resistive strengthening, functional activities, walking, and an Adeli suit. Similar qualitative findings were found in this study compared to

Christy et al.[10] including improvements in motor function with rapid goal attainment, stress on caregivers due to time commitment, and fatigue of children. Caregivers voiced difficulties with logistics and scheduling but quickly reiterated the positives of the intensive program outweighed these difficulties.

Clinical Implications

Pediatric therapists often play a vital role in the life of a child with a disability. Caregivers can spend a substantial amount of resources, both emotional and financial, in securing appropriate therapy for their children. Data from this study may assist families making decisions regarding intervention intensity and therapy approaches.

Specific clinical recommendations are provided for caregivers and clinicians from results of this study. Short, intensive NDT therapy from skilled clinicians improved function. Intervention intensity with increased total time of therapy contributed to quicker, successful functional outcomes; however, caregiver stress and child fatigue are factors to be considered. Clinicians can assist families in weighing benefits and challenges of intensive intervention. Information sharing by families participating in past intensive intervention may assist potential participating families with future planning and logistical problems. Anticipating goals while planning for intensive intervention is recommended. Goals should be written collaboratively and objectively (using SMART guidelines) focused on motivational activities. The use of outcome measures, such as the GAS and COPM, can be easily implemented in the clinical setting for monitoring progress and change. Additional tools appropriate for clinical settings and easily administered by experienced therapists should further be explored.

Special attention is recommended during matching of pediatric therapists for individual children. Trust and rapport should be established early in the therapeutic relationship, or therapists should be changed. Caregivers are vital to the team, and collaboration outside of and during intervention should be a priority. Professionals of varying disciplines should communicate discipline-specific goals, potentially resulting in increased practice and repetition in each therapy session. Collaboration will likely impact the improved functional performance of children. Empowering caregivers with knowledge is a key component to successful therapy. Home programming was highly valued including pictures and text for practice and carry-over in multiple settings. One of the most critical components for successful therapy was open communication among all individuals involved in the children's intervention.

Limitations of the Study

Five primary limitations are identified in this research. The small sample size for the quantitative aspect of this study is the first limitation. According to evidence-based practice guidelines, quasi-experimental quantitative studies with a small sample size (n=16) are a level III on Sackett's level of research evidence.[24] The sample size (n=13) of the caregivers interviewed for this study was appropriate for the qualitative aspect of the research. The sample size (n=16) of the children used as subjects for the quantitative part of the study was small. Although the researcher had statistically significant results indicating the study was not underpowered, generalizations are not recommended due to the small sample size.

The second limitation is a convenience sample was used from one geographical location, limiting diversity in both the parent and child participants. A few families participated from other states, but the majority of the families lived in Wisconsin. Families with limited financial resources were unlikely to participate in this intensive program, but many families accessed private funding, grants and insurance assistance.

A third limitation of this study was the relatively short time period (1-2 weeks) for the intervention with no follow-up of goal attainment afterward. Financial limitations for longer intensive programs are a barrier, and only two of the children were able to participate all day in the two week intensive program. Because the therapists treating the children were from many different areas of the country and not the regular therapists, follow-up data were unable to be collected for this study. Development of a mechanism for follow-up scoring of goal retention after completing the intensive program would be helpful to investigate the long-term effects of the intervention.

A fourth limitation of the study was control of the many variables present in children with disabilities that are difficult with research. Although the children acted as their own controls in the quantitative part of the study, they were not a homogeneous sampling. The large age range (1 to 17 years) contributed to variability, and all children had differing neuromotor diagnoses and functional levels (e.g. CP, dystonia with varying GMFCS Levels). There was no control of potential influences in participant (child) history of past medical procedures including surgeries, differing levels of regular therapy in different settings, and attendance and frequency of previous therapies and intensive programs. Randomization and blinding were not part of the mixed method design. Although specific criteria were followed for the qualitative aspect of the research, the PI served as the sole interviewer, and respondent bias may be present.

The fifth limitation is the varying length of time of the NDT intervention ranging from 2-4 hours a day (half days vs. full days, respectively). Although testing pre- and post-intervention was completed each week for each of the children, varying intervention time occurred. Some younger children participated half days (appropriate for their age group), while some children participated full days. The majority of participants attended one week of the intensive program, but two children attended full days for the entire two week program.

Recommendations for Future Research

This study was the first use of a mixed method design to examine intensive NDT intervention. Continued research using mixed method designs to capture caregivers', therapists' and clients' perceptions of intervention, and appropriate quantitative tools for examining functional change with pediatric therapy are recommended. Further research is required to support improvements in insurance coverage of intensive interventions. Investigation of optimal intervention frequency for retention and generalization of skills, and varying lengths of intensive programs is warranted. In addition, research on appropriate quantitative outcome measures for capturing intervention effects on efficient functional skills is needed. Due to the findings of this study, the collaborative aspect of intervention and its effects on goal attainment require more exploration.

Qualitative research is underutilized in current research in pediatric therapy. Using phenomenological methods, many questions could be explored including therapists and clients' perceptions of intensive therapy, home programs and education, methods to empower caregivers, and suggestions for improving services for children with disabilities.

Summary of Study

Research Purpose and Questions

In the first chapter of this study, the purposes of the research were presented including: 1. to investigate and report on parents of children with disabilities' perceptions regarding their child's participation in an intense therapy treatment program consisting of neurodevelopmental treatment (NDT); and 2. to examine if there is a significant difference in functional skills of

children with CP and other neuromotor disorders after an intensive NDT program with therapeutic handling measured by the Goal Attainment Scale (GAS) and the Canadian Occupational Performance Measure (COPM). Using a mixed method design, both qualitative and quantitative aspects of an intensive therapy program utilizing NDT were explored.
A qualitative phenomenological approach of inquiry was conducted through direct interviews and observations with parents whose children participated in the intensive NDT program. Quantitatively, data were collected weekly on the children pre- and post-NDT intervention using both the Goal Attainment Scale (GAS) and the Canadian Occupational Performance Measure (COPM). To explore the effects of the intensive program, the researcher combined the caregivers' perceptions of the intensive program experience with quantitative changes in goals set for the children.

The first research question (qualitative design) explored was: "What has having your child participate in this intensive NDT program been like for your family and you as parents of a child with a disability? The second research question (quantitative design) explored was: "Is there a significant change in functional motor skills as measured weekly by the GAS and the COPM in children with CP and other neuromotor disorders after receiving a short-term intensive program of NDT therapeutic handling?"

Literature Review

The second chapter of this study included reviewing pertinent literature on commonly used therapy interventions of varying intensities and their effectiveness in pediatric PT. Emphasis was on reviewing published studies where researchers concentrated on examining increased intervention intensity with special attention to studies evaluating NDT with increased intervention intensity.

The literature review on intensive therapy revealed intensity of intervention as a key factor affecting positive outcomes with therapeutic interventions. Many researchers conducted studies supporting medical procedures such as botulinum toxin A (BTX-A) injections or selective dorsal rhizotomies (SDR), partial body weight supported treadmill training (PBWSTT), constraint-induced therapy and alternate therapy methods (Adeli suit, Johnstone splints, and casting) with increased intensity. Limited quantitative studies were found on intensity of direct, hands-on therapy such as NDT and only 1 qualitative study warranted further investigation.

Research Methods

The third chapter highlighted the study design. A mixed method design was employed for both qualitative and quantitative evidence. Qualitatively, a phenomenological design was employed exploring lived experiences of 13 caregivers of children with disabilities participating in a short-term intensive NDT program. Evidence was derived from first-person accounts of caregivers with children having special needs who had insight and experience from participating in the short-term NDT intensive program. Phenomenological investigation was used to describe the meaning of several individuals experiencing particular shared phenomena or lived experience. Creswell's[22] framework for phenomenological study was implemented for data collection and analysis. Data collection included demographic record review, observations, open-ended interviews using a semi-structured interview guide, and extensive field notes. Data analysis involved horizonalization, theme development, textural and structural descriptions and composite description capturing the "essence" of the phenomenon.[22]

Quantitatively, a quasi-experimental (repeated measure) design was used to examine functional differences of children with disabilities participating in the short-term intensive NDT programs. Pre- and post-test data were obtained using the GAS and COPM surrounding the intensive intervention program. The children of the parents participating in the qualitative research served as subjects for the quantitative design with the children acting as their own controls.

The research setting included two churches where the intensive programs were held in Milwaukee, Wisconsin. The caregivers and their children were purposefully selected from the NDT intensive program applications provided by Partners for Progress, a not-for-profit entity sponsoring the NDT intensive programs.

Results and Presentation of the Data

In the fourth chapter, data were reported from the mixed method design. Demographic findings were discussed for both the adult and children participants in the study. For the first research question, a narrative with individual descriptions of the families was provided. Significant statements were coded using NVivo 9 (software program for qualitative data) with seven themes emerging. Detailed textural and structural experiences of the intensive program through verbatim examples from the interview transcripts were used to support the theme construction. An individualized textural and structural experience of one caregiver was shared. Finally, a composite description incorporating both the textural and structural descriptions was provided relaying the essence of the NDT intensive program. For the second research question, quantitative results using both the GAS and COPM of all child participants were detailed. Statistically significant differences ($p<.001$) were found pre-to post-weekly NDT intensive intervention on the GAS and COPM mean scores.

Summary, Implications, and Outcomes

In the final chapter, results were discussed with identified methodological strengths and limitations provided and linkage made to similar studies in the literature. Recommendations were made for current pediatric clinical practice, and suggestions for further research were addressed.

Conclusions

Intensity of intervention is a hot topic currently in pediatric research. Caregivers of children with disabilities voiced positive support for an intensive NDT program. Increased intensity of intervention using the NDT approach had a positive functional impact on children. The GAS and COPM were found to be clinically relevant, inexpensive objective outcome measures for examining changes in function pre-to post-intervention during a short time period. Collaboration and home programming was of utmost importance for optimal outcomes and caregiver satisfaction.

Coinciding with the changes of the last two decades in prioritizing family-centered services (FCS), conducting qualitative research is an appropriate forum for giving parents a voice regarding their child's therapy. Rosenbaum[25(p.99)] discussed "how much richer our studies have become with the active input of families." This study involved caregiver's opinions on a unique intervention option for their children.

Collaboration, unique qualities of therapists (NDT expertise and compassion), realistic, specific goals using SMART techniques, and home programming were all benefits of the NDT intensive program. Difficulties with insurance and logistical scheduling required for the intensive were voiced. Overriding, was the reality that each child and family is unique and require individualized intervention to best meet their needs. A holistic approach to family-centered care was preferred. An NDT intensive program may be an excellent option for some families seeking increased intensity of therapy for their children to assist with functional improvements.

Closing Comments

As an NDT pediatric physical therapist for 27 years, it was a rewarding experience to research NDT intensive intervention. Performing qualitative research requires a strong commitment to the study with field time and data analysis being a time-consuming process, but hearing the experiences of caregivers with intensive intervention was invaluable. My belief is parents are the experts and have so much more to teach us about their lives involving their children. The complexities with researching intervention quantitatively and qualitatively continue. Completing this research satisfied my desire to validate qualitative and quantitative changes through intensive NDT intervention and strengthened my desire to empower parents to use their voice so we can improve therapeutic intervention choices for their families.

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APPENDICES

Appendix A: Qualitative Interview Guide

Qualitative research-outcome measures for NDT Intensive Research

Parent questionnaire using the following Interview Questions:

1. What has been you, your child's, and your family's experience of having your child participate in this five (or ten) day intensive NDT program? Probe: Describe the process; tell me what brought to the program and what instructions or information you were given prior to the process. How did you feel about this program initially?

2. How were you and your child's needs met through this NDT program?

3. What were the hopes for you and your child during this intensive NDT program?

4. What needs or hopes for you or your child's were unmet with this intensive NDT program?

5. What could have been done to better help you with this whole experience?

6. What has been the hardest part for you and your child about this program?

7. How have you dealt with any difficulties with the program?

8. What has been easiest part for you and your child about the program?

9. How has this intensive program differed from other therapy your child has received?

10. Was there anything that happened specifically (positively or negatively) that you would like to share about the intensive NDT program?

11. Describe your experience with the therapists during this program.

12. If there were three top things you could discuss or pass on to other parents about the intensive NDT program -what would they be?

13. What would you do differently or what would you tell other parents or children to help them with this NDT program.

14. (if applicable-asked only if family has participated in the intensive NDT program previously) How was the home program for you and your family?

15. Is there anything else you would like to add?

Interviews will be performed after completion of the intensive NDT program with each interview session following the same protocol. The interview protocol will consist of the following:

1. Introduction from the researcher and a warm welcome to the participant (try to build trust and rapport at entry stage).
2. Before interview begins, review consent, assent (if applicable) and demographic forms to ensure completion of forms and for continued consent for interview.
3. Before the interview begins, ask if participant is comfortable and needs anything.
4. Ask if the participant is ready to begin the interview, and turn the tape recorder on.
5. If a break is needed for the participant, provide this whenever necessary.
6. Ask semi-structured interview questions allowing time for formation of answers and clarifications from participants.
7. Take field notes during the interview including an evaluation report of the researcher’s own experiences, thoughts, and feelings.
8. At the end of the semi-structured question format, be sure the participant has nothing else to add for the interview.
9. Turn the tape recorder off, and thank the parent graciously for participating in research.
10. Give thank-you gift card to the participant.

Appendix B: Demographic and Descriptive Data Form

DEMOGRAPHICS AND DESCRIPTIVE DATA FORM

Child Letter/Number:

Child's Diagnosis:

GMFCS Level:

Child's DOB: **Current Age:** **Grade Level:**

Medical History: (including surgeries)

Classroom Setting (if applicable):

Services/Support (both in and out of school-e.g. PT, OT, SLP, VI, A/T):

Caregivers:

Participation Abilities:

Participation Limitations:

Functional Abilities:

Functional Limitations:

Parent Goals:

Therapy Goals:

Appendix C: Field Notes

Short-term, Intensive Neurodevelopmental Treatment (NDT) Program Experiences of Parents and their Children with Disabilities

QUALITATIVE RESEARCH: FIELD NOTES

Interview Date:
Start Time:
Ending Time:
Pre-Interview Goals: Learn about the NDT course experience through parents' perceptions
Location of the Interview:
Description of the Environment: (physical space, equipment)
People Present: (any activities or interactions)
Content of Interview: (key words, topics, focus, anything that stood out)

Non-verbal behavior: (voice, posture, eyes, gestures)

Researcher's impressions: (discomfort with content or emotional responses)

Technological problems: (did tape recorder work)

Impact of researcher positioning: (positive or negative)

Analysis: (questions, hunches, familiar themes, data trends, emerging patterns)

What were the main issues and themes from this contact?

Summarize the information obtained from interview:
Positive perceptions/experiences:

Negative perceptions/experiences:

Family Needs:

Support (or lack of support) provided:

What else was interesting/illuminating, or important about this contact?

Any important quotes?

Anything new to add for next contact/ or desired information not obtained and would like to reword:

Appendix D: Contact Summary Forms

Contact Summary Forms for Parents/Caregivers, Children, Therapists

ATTENDANCE DATA COLLECTION FORM

Parents/Caregivers

Child	Day 1 am/pm	Day 2 am/pm	Day 3 am/pm	Day 4 am/pm	Day 5 am/pm	Day 6 Am/pm	Day 7 am/pm	Day 8 am/pm	Day 9 am/pm	Day 10 am/pm
1.										
2.										
3.										
4.										
5.										
6.										
7.										
8.										
9.										
10.										
11.										
12.										
13.										
14.										
15.										

ATTENDANCE DATA COLLECTION FORM

Children

Child	**Day 1 am/pm**	**Day 2 am/pm**	**Day 3 am/pm**	**Day 4 am/pm**	**Day 5 am/pm**	**Day 6 am/pm**	**Day 7 am/pm**	**Day 8 am/pm**	**Day 9 am/pm**	**Day 10 am/pm**
1.										
2.										
3.										
4.										
5.										
6.										
7.										
8.										
9.										
10.										
11.										
12.										
13.										
14.										
15.										

THERAPIST COLLABORATION- DATA COLLECTION FORM
(PT/OT/SLP)

Child	Day 1 am/pm	Day 2 am/pm	Day 3 am/pm	Day 4 am/pm	Day 5 am/pm	Day 6 am/pm	Day 7 am/pm	Day 8 am/pm	Day 9 am/pm	Day 10 am/pm
1.										
2.										
3.										
4.										
5.										
6.										
7.										
8.										
9.										
10.										
11.										
12.										
13.										
14.										
15.										

Appendix E: Data Collection Forms

SUMMARY DATA COLLECTION FORM

child	**Subject Consent form**	**Parental Consent form**	**Assent form**	**Demo graphic form**	**GAS1**	**GAS2**	**COPM1**	**COPM2**	**Field Notes**	**Interview**
1.										
2.										
3.										
4.										
5.										
6.										
7.										
8.										
9.										
10.										
11.										
12.										
13.										
14.										
15.										

Goal Attainment Scale
NDT Intensive Research Data Collection Forms for GAS (for therapists)
GAS Goals-Form 1

Child's Number______________________________________ Age:________________

Circle one: Week 1 Week 2

Level of Attainment	Scale 1	Scale 2	Scale 3	Scale 4	Scale 5
Much less than expected -2					
Somewhat less than expected -1					
Expected level of outcome 0					
Somewhat more than expected +1					
Much more than expected +2					
COMMENTS					

Developed by Debbie Evans-Rogers, PT, MS, PCS-RMU-Intensive dissertation-2010

GAS Goals-Form 2 (more room for therapists to write)

Child's Number______________________________________

GAS GOALS

Goal 1

Goal 2

Goal 3

Canadian Occupational Performance Measure

Data Collection Form: COPM Scores-Form 1 (using GAS goals)

Child's Number______________________________________

GAS Goals	Pretest (Time 1) Importance	Pretest (Time 1) Performance	Satisfaction	Posttest (Time 2) Importance	Performance	Satisfaction
1.						
2.						
3.						

Summary:

Performance1:	Performance2:
Satisfaction1:	Satisfaction2:

NDT Summary Form (for each individual child)

CHILD SCORES Child_________

Goal Attainment Scale (GAS)

Week 1	Pre-test	Post-test
Goal #1		
Goal #2		
Goal #3		
Goal #4		
Goal #5		

Week 2	Pre-test	Post-test
Goal #1		
Goal #2		
Goal #3		
Goal #4		
Goal #5		

Canadian Occupational Performance Measure (COPM)

Week 1

	Time 1			Time 2		
Problems	Importance	Performance	Satisfaction	Importance	Performance	Satisfaction
1.						
2.						
3.						
4.						
5.						

Week 2

	Time 1			Time 2		
Problems	Importance	Performance	Satisfaction	Importance	Performance	Satisfaction
1.						
2.						
3.						
4.						
5.						

Developed by Debbie Evans-Rogers, PT, MS, PCS-RMU-Intensive dissertation-2010

Appendix F: Guidelines for Goal Writing: GAS and COPM

Goal Attainment Scaling (GAS) & Canadian Occupational Performance Measure (COPM)

First, I wanted to be sure each of you knew how much I appreciate you assisting with this research. It is so important to get quantitative and qualitative data to support intensive therapy and NDT! Thank You!!!

The GAS started as a method to evaluate mental health treatment and expanded to include applications in a variety of settings including rehabilitation. I am using it for this research because of its ability to assess change brought about by intervention. The Canadian Occupational Performance Measure (COPM) has been used to identify and prioritize everyday issues impacting occupational performance. It has been used often as a self-perception and in this research it will include parent perceptions. I like it because of the participatory process producing a quantitative score. Both the Goal Attainment Scale and Canadian Occupational Performance Measure are really easy to use! And I hope this helps with planning for their use in the intensives.

I'll start with the GAS information first:

1. Talk to the parents/caregivers/children/therapists (if available) about what is important for them to improve functional abilities. For the intensive program, a few goals work well. (I think two or three are best- but the GAS provides a conversion method for up to eight goals).
2. Choose a title for the goal (e.g. sitting, aug. comm. Etc)
3. Select an indicator for each goal (the quantitative piece that indicates if the goal was met)
4. Write what is the expected level of achievement for the goal. This is what you would like to see accomplished at the end of one week of the intensive treatment. *We will be checking goals after each week of the intensives because some children will only be attending one week vs. two. It is okay if the goals are not met after one week and you continue the same goal for the next week- We will just need to score each of the goals after each week of the intervention.

- this is the hardest part- the therapists should attempt to accurately predict the level of performance the child is expected to achieve after a week or two of the intensive intervention.
- Once a quantitative amount is specified, to the best of your ability you identify equal increments above and below the expected level of performance.
- Using **SMART** goals can help: Goals that are **S**pecific, **M**easurable, **A**chievable, **R**ealistic/Relevant, and **T**imed

A five-point Likert scale is used. When scoring the GAS, a value (+2, +1, 0, -1, -2) is assigned to each goal depending on the level that has been achieved. The 0 (zero) score is to be used as the "predicted expected level of performance". This is the goal you expect your child to achieve. A -1 score indicates somewhat less than expected outcome, -2 is much less than expected outcome; and a +1 score is a somewhat more than expected outcome, and a +2 is a much more than expected outcome.

Here are a few examples to help:
Let’s say you want a child to be able to sit on his own:

Start with writing the goal you want the child to achieve:
J. will sit independently on small height (5 inches) with pelvis perpendicular and using medial and lateral support while playing with toy placed forward at eye level for 10 seconds.

This is the expected level of outcome or the 0.
Then you write the -2 goal and -1 goal (much less than expected and somewhat less than expected. Example: for the -2: same goal but for 4 sec., -1 for 7 sec. For the +1 and +2 goals: somewhat more than expected and much more than expected: +1 for 13 sec., and the +2 for 16 sec.
I used an increment of 3 seconds trying to keep the scale of the goal with equal increments.
Here is another example from an article by Mailloux et al. (2007):

The goal was for food tolerance:
-2: tolerates the family eating area during mealtime without signs of discomfort or distress (crying, gagging, whining, or leaving table or room) 4 of 5 opportunities
-1: tolerates 2 new foods on table or other family members’ plates without signs of discomfort or distress (crying, gagging, whining, or leaving table or room) 4 of 5 opportunities
0: tolerates 2 new foods placed on own plate without signs of discomfort or distress (crying, gagging, whining, or leaving table or room) 4 of 5 opportunities
+1: takes a bite of 2 new foods during a meal without signs of discomfort or distress (crying, gagging, whining, or leaving table or room) 4 of 5 opportunities
+2 eats multiple bites of 2 new foods without signs of discomfort or distress (crying, gagging, whining, or leaving table or room) 4 of 5 opportunities

One more example for augmentative communication:

+2: will interact with cause/effect using his device for 1 minute (including selecting icon, getting toy)
+1: will interact with cause/effect using his device for 3 minutes (including selecting icon, getting toy)
0: will interact with cause/effect using his device for 5 minutes (including selecting icon, getting toy)
1: will increase interaction with cause/effect using his device to 7 minutes (including selecting icon, getting toy)
2: will increase interaction with cause/effect using his device to 10 minutes (including selecting icon, getting toy)

Now for the COPM:
There are three questions concerning the GAS goals you just wrote to ask the parent/child: They are regarding IMPORTANCE, PERFORMANCE, and SATISFACTION
With each goal you write you ask 1st:
On a scale of 1-10 with 1 being not important at all, and 10 being extremely important- how important is this activity?

Then you ask the parent/caretaker or child:
On a scale of 1 to 10 with 1 being not able to do it, and 10 being able to do it extremely well- How would you rate your performance of this activity today?

Then you ask the parent/caretaker or child:
On a scale of 1 to 10 with 1 being not satisfied at all, and 10 being extremely satisfied-How would you rate your satisfaction of this activity today?

> **I copied small cards for you to help with this so you don't have to remember it and provided sheets for goal writing and scoring the GAS and COPM.

I will be at the intensives both weeks and will be more than happy to help with goal writing on that first day.

THANK YOU, THANK YOU, THANK YOU!!! ☺ Debbie Evans-Rogers, PT, MS, PCS

Appendix G: NDT Intervention Details Form

(adapted from chart used by Ustad et al.,[1] 2009)

1st do thorough eval and use team collaboration	Functional Activity/Goal	Child's Starting Position	Activities Initiated by Child	Activities Imposed by Therapist	Key Point of Control	Handling Inhibition (-) or Facilitation (+)	Environment-al Adaptation or Equipment used
Prep activities							
A, B, C's Alignment, BOS, COM							
Core m. activation							
Elongation/ activation							
Practice time, repetition							

Guidance (fac. or inhibition) was provided by direct handling for improving body alignmt, wt. bearing, wt. shifting, midrange control, prox. holding and variety of movemt

1. **Ustad T, Sorsdahl A, Ljunggren A. Effects of Intensive Physiotherapy in Infants Newly Diagnosed with Cerebral Palsy. *Pediatric Physical Therapy.* 2009; 21:140-149.**

Appendix H: Basic NDT Pediatric Course Information (from the Neurodevelopmental Treatment Association (NDTA)

NDT/Bobath Certificate Course in the Treatment and Management of Children with Cerebral Palsy and other Neuromotor Disorders

Sample Information for NDTA Course Participants

Course Objectives

Identify the basic principles of Neuro-Developmental Treatment (NDT) and the theoretical assumptions which support these principles.

Analyze typical and atypical patterns of posture and movement in children with cerebral palsy and similar neurological impairments.

Perform assessments and develop treatment protocols incorporating NDT principles.

Perform treatment strategies to obtain objectives and progress treatment to improve functional skills.

Course Content

Basic principles of NDT and theoretical assumptions which support these principles.

Typical and atypical development of postural control and movement necessary for functional motor skills (gross motor, fine motor, respiratory, phonatory, oral motor).

Impairments and functional limitations of children with various types of cerebral palsy.

Assessment and treatment to improve functional skills in children of various ages and types of cerebral palsy.

Team approach including family as team member.

There will be considerable laboratory sessions to learn and practice the handling and treatment skills. You will assess and treat children with a partner. The instructors will give you verbal and physical feedback and assistance. Please let one of the instructors know if you are not receiving adequate assistance.

There will be reading and written assignments during the course. You will meet with an instructor midway through the course to discuss your strengths and areas of emphasis for the remainder of the course. In the last week of the course you will meet to discuss your progress and to give feedback about the course to the instructor. Upon completion of the course objectives, a certificate of successful completion is awarded (detailed objectives are included in the course curriculum outline available at the course). We will make every effort to help you complete these objectives during the course. However, if you do not, a plan can be worked out with the coordinator instructor for you to

complete them within two years.
Bring to course:

Cloth bodied doll, 24" - 30" long

Any favorite toys you use in therapy

Therapy ball if desired (Some will be available at course)

Required Readings:

Neuro-Developmental Treatment Approach: Theoretical Foundations and Principles of Clinical Practice, Janet M. Howle in collaboration with NDTA Theory Committee

Recommended Readings:

The Bobaths, J. Schleichkorn, PhD, PT, Therapy Skill Builders.

Motor Development in Different Types of Cerebral Palsy, Berta and Karel Bobath.

NDT/Bobath Pediatric Minimal Core Course Content

I. BASIC CONTENT

	Lecture Hours	Non-Lecture Hours
1. Introduction to NDT	2.5	0.0
2. Classification and different types of cerebral palsy	6.5	1.5
3. Postural control	2.0	3.0
4. Normal development of movement and postural control	9.0	4.0
5. Abnormal development	6.0	3.5
6. Evaluation/Assessment	2.0	4.0 + 3.0
7. Treatment	9.0	38.0
8. Parent training and home management	1.0	1.0
9. Analysis and facilitation of movement	0.0	40.0
10. Patient treatment sessions	0.0	45.0
11. Teamwork	1.0	0.0
12. Neurophysiology	10.0	2.0
13. Occupational therapy	0.0	28.0
14. Speech therapy	0.0	25.0
15. Miscellaneous	12.0	2.0
SUBTOTALS	61.0	200.0

TOTAL HOURS = 261.0

Appendix I: Consent Forms

Rocky Mountain University of Health Professions
Consent to Participate as a Research Subject
Parent Interview

Short-term, Intensive Neurodevelopmental Treatment (NDT) Program Experiences of Parents and their Children with Disabilities

Investigators:

Debbie Evans-Rogers, PT, MS, PCS, Doctoral Candidate for Doctor of Science in Pediatrics
Rocky Mountain University of Health Professions-Provo, Utah
(832) 480-6755

Dr. Jane Sweeney, PT, PhD, PCS, FAPTA
Professor and Graduate Program Director-School of Rehabilitation Sciences
Rocky Mountain University of Health Professions-Provo, Utah
(253) 265-3866

Dr. Patricia Holden-Huchton, RN, DSN, CNE
Dean and Professor, College of Nursing
Texas Woman's University
(940) 898-3515

Dr. Pamela Mullens, PT, PhD
Coordinator Instructor for Neurodevelopmental Treatment-Pediatric and Adult patients
Private practice-Seattle, Washington
(206) 524-1743

Investigator's Statement

We are asking you to be in research study. The purpose of this consent form is to give you information you will need to help you decide whether to participate in the study or not. Please read the consent form very carefully. You may ask questions about the purpose of the research, what we would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this consent form that is not clear. When we have answered all you questions, you can decide if you want to be in the study or not. This process is called 'informed consent.' We will give you a copy of this form for you records.

Purpose of the Study

The purpose of this research study is to explore parents' perspectives about their child's participation in an intensive 5-10 days, 2-4 hours a day, neurodevelopmental treatment (NDT) program, and to examine how NDT treatment affects movement and functional independence in your child. It is conducted by Debbie Evans-Rogers, a doctoral candidate in the Pediatric Science program at Rocky Mountain University of Health Professions (RMUoHP). You were selected because you are the parent of child participating in the NDT handling intensive program through Partners for Progress.

Description of the Study

This study will incorporate both using interviews which is called qualitative research, and collecting numerical data which is called quantitative research. The anticipated number of parent participants for this research is eight to fifteen. Parents of both male and female children aged one to twenty one years old with a disabling condition participating in the five or ten day intensive program will be recruited for this study. To be eligible for this research study:

1. Parent must have a child ranging from the age of one to twenty one with the diagnosis of Cerebral Palsy (CP) or other neuromotor condition participating in the five or ten day intensive program;
2. Parent must participate in the majority (greater than 50%) of the five or ten-day intensive treatment sessions.

A personal interview of one-hour length, a first evaluation or pretest using the Canadian Occupational Performance Measure (COPM) and Goal Attainment Scaling (GAS) requiring a maximum time of 25 minutes, 1-2 daily, two hour intervention sessions, and a second post-test using the COPM and GAS of 25 minute duration after each week of intervention will be scheduled at a time convenient for you.
The location of the research study will be at the St. Dominic Catholic Church in Brookfield, Wisconsin or the Gethsemane United Methodist Church in Pewaukee, Wisconsin where the Partners for Progress handling intensive programs are performed.

The study procedures for the parents with children participating in the intensive program will include:

1. You will be asked to fill out background information about your child prior to the course. (this is part of qualitative demographic information).
2. You will be interviewed by this researcher in a 60 minute session that will be recorded using a tape and/or video recorder. Field notes by the researcher may be taken during the interview to ensure accuracy of information given. Some of the interview questions asked may be sensitive in nature and will require your personal insight. For example you will be asked “what were the hopes for you and your child during this intensive program?” You may refrain from answering any question or item in any of the questionnaires, tests, or interviews that you do not want wish to answer. After all interviews have been performed, the tape recorded interviews will be transcribed (or typed with each word verbatim) and the researcher will summarize the findings from all parents interviewed. The use of medical information that has been supplied by you, therapy notes, and other records or information about your child including photographs and videotapes may be included in the use of this research study.

What is Experimental in This Study

None of the intervention procedures or questionnaires used in this study are experimental in nature. The only experimental aspect of this study is the gathering of the information for the purpose of analysis.

Potential Risks, Stress, or Discomfort

There are minimal risks to you associated with your participation with this research study. Because of the personal nature of questions asked during the interview process, your sharing of personal experiences may cause feelings and memories that are unpleasant or stressful. You are allowed to not answer any questions you wish, and can take a break at anytime you deem necessary. Trained therapists familiar with the GAS and COPM will assist you with ideas for goals if needed and scoring procedures. The greatest inconvenience to you will be your participation in the daily intervention sessions, requiring planning from you to attend the majority of the sessions.

Potential Benefits from Participation

I cannot guarantee, however, that you will receive any known benefits from participating in this study. The benefits of participating in this study on the intensive program may be that your child gets stronger and is able to improve with functional abilities. By participating in the interviews for this research study, other families of children with special needs may benefit from the knowledge gained regarding an intensive Neurodevelopmental program. Your personal thoughts and feelings about the NDT program experience will be heard and documented.

Alternate Methods of Treatment

You may choose not to participate in this study. You may continue with the usual care and therapy with your child, and participate in this intensive program even if not participating in this research.

Confidentiality

Strict confidentiality will be maintained to the extent allowed by law. Individual identifying information obtained from this research study will be kept confidential. Where possible, all identifying references of each participant will be removed and
Replaced by an alphabetical and numeric code identifier. All data pertaining to your interviews or your child's information will be stored in a locked file only accessible to the investigator. The master list linking the codes to you and your child's name will be kept in a separate locked file cabinet. Only the researcher involved in the study, the transcriptionist, and the instructors at RMU will have access to the data collected. Additional investigators and transcriptionist will be trained in all confidentiality procedures and policies of the study. The audiotapes used to record the interview will be maintained until the interview is transcribed fully and the tape will then be erased. The participant will be allowed to review the transcribed data and edit the tape prior to publication. All data pertaining to this research study will be retained for 7 years as recommended by RMUoHP IRB policy. The data may be presented at conferences, courses, or published but no personal identifying information will be released. Videotapes will be protected in a locked cabinet. You will be asked to consent to use the videotapes for educational purposes for training pediatric therapists in the treatment of children with neuromotor disabilities, and kept indefinitely, with you (the parent's) permission. You will have the option to have their child's face masked for confidentiality purposes. If you agree, the videotapes will be kept indefinitely for educational and professional presentations and not for commercial use. If you do not agree, the tapes will be erased in seven years and will not be used for educational or professional purposes. If you have provided consent of photographs, if this research is accepted for

publication, you will be asked and consent will be obtained before any photograph may be published in the research article and/or poster presentation.

Incentives to Participate

Upon completion of this study, a small token of thanks by means of a gift card consisting of $10.00 from Starbuck's will be provided to all families participating in the study.

Costs and /or Compensation for Participation

There will be no costs incurred to the participant and parents to participate in this research study (other than the cost required by Partners of Progress for the NDT intensive program).

Voluntary Nature of Participation

Participation in this study is strictly voluntary. Your choice of whether or not to participate will not influence your future relations with Rocky Mountain University of Health Professions or Partners for Progress. If you decide to participate, you are free to withdraw your consent and to stop your participation at any time without penalty or loss of benefits to which you are allowed. You have the right at any time to decline or stop participation, withdraw consent from participation, or refuse to answer any questions without penalty or loss of benefits from which you are allowed from this research. If you choose to stop your participation in this research, all information obtained will not be used in this research project.

Questions about the Study

If you have any questions about the research now, please ask. If you have questions later about the research, you may contact Debbie Evans-Rogers by phone: (281) 534-6755 or via email: drogers187@att.net. If you have questions regarding your rights as a human subject and participant in this study, you may call the Institutional Review Board at Rocky Mountain University of Health Professions. The telephone number of the IRB Committee is (443) 926-6243. You may also write to the committee at irb@rmuohp.edu or fax (801) 734-6771.

Consent to Participate

The Institutional Review Board Committee at Rocky Mountain University of Health Professions has approved this consent form as signified by the Committee's stamp. This consent form must be reviewed at least once every year and expires one year from the approval date indicated on the stamp.

Printed name of Investigator	**Date**	**Signature of Investigator**	**Date**

Subject's Statement

This study has been explained to me. I volunteer to take part in this research. I have had a chance to ask questions. If I have questions later about the research, I can ask one of the researchers listed above. If I have questions about my rights as a research subject, I can call the Rocky Mountain University of Health Professions Institutional Review Board Committee at (443) 926-6243. My signature also indicates that I can change my mind and withdraw my consent to allow my child to participate at any time without penalty. I will receive a copy of this consent form.

I understand that my signature on this form constitutes my informed consent to act as a subject in this research project. Participation in this study is entirely voluntary. No medical service or compensation is provided to subjects by the university as a result of injury from participation in this research.

Please initial the appropriate line.

_____1. I agree to have my interview audiotaped only.
_____2. I agree to have my interview audiotaped; and to have images or videotapes taken of me as part of the regular intensive program to be included in this study.
_____3. I do not want pictures or videotaping to be taken/used for study or presentation purposes.

____________________________	________________________	_______
Printed name of Participant	**Signature of Participant**	**Date**

Rocky Mountain University of Health Professions
Parental Permission for Participation of a Minor

Short-term, Intensive Neurodevelopmental Treatment (NDT) Program Experiences of Parents and their Children with Disabilities

Investigators:

Debbie Evans-Rogers, PT, MS, PCS, Doctoral Candidate for Doctor of Science in Pediatrics
Rocky Mountain University of Health Professions-Provo, Utah
(832) 480-6755

Dr. Jane Sweeney, PT, PhD, PCS, FAPTA
Professor and Graduate Program Director-School of Rehabilitation Sciences
Rocky Mountain University of Health Professions-Provo, Utah
(253) 265-3866

Dr. Patricia Holden-Huchton, RN, DSN, CNE
Dean and Professor, College of Nursing
Texas Woman's University
(940) 898-3515

Dr. Pamela Mullens, PT, PhD
Coordinator Instructor for Neurodevelopmental Treatment-Pediatric and Adult patients
Private practice-Seattle, Washington
(206) 524-1743

Investigator's Statement

You are being asked to allow your child to participate in a research study. The purpose of this consent form is to give you information that you will need to help you decide whether to allow your child to participate in the study or not. Before you give your permission for your child to participate, it is important that you read the following information and ask as many questions as necessary to be sure you understand what your child will be asked to do. This process is called 'informed consent.' We will give you a copy of this form for you records.

Purpose of the Study

The purpose of this research study is to explore parents' perspectives about their child's participation in an intensive 5-10 days, 2-4 hours a day, neurodevelopmental treatment (NDT) program, and to examine how NDT treatment affects movement and how your child functions. It is conducted by Debbie Evans-Rogers, a doctoral candidate in the Pediatric Science program at Rocky Mountain University of Health Professions (RMUoHP). Your child was selected for participation because an application for attending the NDT handling intensive program was filled out by your family for your child's participation in the intensive program.

Description of the Study

This study will incorporate both using interviews which is called qualitative research, and collecting numerical data which is called quantitative research. The anticipated number of parent participants for this research is eight to fifteen; and the anticipated number of children participants is twenty (more participants are required for the quantitative data). Male and female children aged one to twenty one years old with a disabling condition participating in the five or ten day intensive program (for quantitative data) and their parents (for qualitative data) will be recruited for this study. To be eligible for this research study:

1. Parent must have a child ranging from the age of one to twenty one with the diagnosis of Cerebral Palsy (CP) or other neuromotor condition participating in the five or ten day intensive program;
2. Child must be aged one to twenty one with a diagnosis of CP or other neuromotor condition affecting their participation and functional abilities;
3. Child must participate in 70% of the five or ten day intensive program and
4. If parent is participating in the qualitative interviews, they must be present in the majority (greater than 50%) of the five or ten-day intensive treatment sessions. (Note: not all children participating in the quantitative data will have a parent that is interviewed for the qualitative data).

The total duration commitment will be one week from July 12-16, 2010; or two weeks from July 12-16, and July 19-23, 2010; or one week October 25-29. 2010; or one or two weeks in July 2011 (date still to be determined). . The total commitment time for the handling intensive program is two to four hours/day with a weekly commitment of 10-20 hours. A personal interview of one-hour length, a first evaluation or pretest using the Canadian Occupational Performance Measure (COPM) and Goal Attainment Scaling (GAS) (requiring a maximum time of 25 minutes), 1-2 daily, two hour intervention sessions, and a second post-test using the COPM and GAS of 25 minute duration after each week of intervention will be scheduled at a time convenient for you. The location of the research study will be at the St. Dominic Catholic Church in Brookfield, Wisconsin or the Gethsemane United Methodist Church in Pewaukee, Wisconsin where the Partners for Progress handling intensive programs are performed.

The study procedures for the children involved in the study will include:

1. You will be asked to fill out background information about your child prior to the course.
2. You will be asked to participate in a short questionnaire prior to and after each week of the intensive program about your child's ability to perform everyday activities called the Canadian Occupational Performance Measure (COPM). A rating on the scale of 1-10 for performance, importance and satisfaction of performance will be scored with your assistance.
3. Your child will be evaluated before and after each week of the intensive NDT program using a functional outcome measure, Goal Attainment Scaling (GAS). You will be asked to assist with goal writing for the GAS.

What is Experimental in This Study

None of the intervention procedures or questionnaires used in this study are experimental in nature. The only experimental aspect of this study is the gathering of the information for the purpose of analysis.

Potential Risks, Stress, or Discomfort

There are minimal risks to your child associated with your participation with this research study. Because of the personal nature of questions asked during the interview process, your sharing of personal experiences may cause feelings and memories that are unpleasant or stressful. Your child will be evaluated by trained therapists familiar with GAS and the COPM. The greatest inconvenience to you will be your participation in the daily intervention sessions, requiring planning from you to attend the majority of the sessions.

Potential Benefits from Participation

I cannot guarantee, however, that your child will receive any benefits form participating in this study. The benefits of participating in this study on the intensive program may be that your child gets stronger and is able to improve with functional abilities. By participating in the interviews for this research study, other families of children with special needs may benefit from the knowledge gained regarding an intensive Neurodevelopmental program. Your personal thoughts and feelings about the NDT program experience will be heard and documented.

Alternate Method of Treatment

You may choose not to participate in this intensive NDT program or in this study. You may continue with the usual care and therapy with your child.

Confidentiality

Strict confidentiality will be maintained to the extent allowed by law. Individual identifying information obtained from this research study will be kept confidential. Where possible, all identifying references of each participant will be removed and replaced by an alphabetical and numeric code identifier. All data pertaining to your child's information will be stored in a locked file only accessible to the investigator. The master list linking the codes to you and your child's name will be kept in a separate locked file cabinet. Only the researcher involved in the study and the instructors at RMU will have access to the data collected. Additional investigators will be trained in all confidentiality procedures and policies of the study. All data pertaining to this research study will be retained for 7 years as recommended by RMUoHP IRB policy. The data may be presented at conferences, courses, or published but no personal identifying information will be released. Videotapes will be protected in a locked cabinet. You will be asked to consent to use the videotapes for educational purposes for training pediatric therapists in the treatment of children with neuromotor disabilities, and kept indefinitely, with the parent's permission. The parent/caregiver will have the option to have their child's face masked for confidentiality purposes. If you agree, the videotapes will be kept indefinitely for educational and professional presentations and not for commercial use. If you do not agree, the tapes will be erased in seven years and will not be used for educational or professional purposes. If you have provided consent of photographs, if this research is accepted for publication, you will be asked and consent will be obtained before any photograph may be published in the research article and/or poster presentation.

Incentives to Participate

Upon completion of this study, a small token of thanks by means of a gift card consisting of $10.00 from Starbuck's will be provided to all families participating in the study.

Costs and /or Compensation for Participation

There will be no costs incurred to the participant and parents to participate in this research study (other than the cost required by Partners of Progress for the NDT intensive program).

Voluntary Nature of Participation

Participation in this study is strictly voluntary. Your choice of whether or not you allow your child to or whether or not you participate will not influence his/her or your future relations with Rocky Mountain University of Health Professions or Partners for Progress. If you decide to allow your child to participate, he/she is free to withdraw their consent and to stop his/her participation at any time without penalty or loss of benefits to which he/she is allowed. You have the right at any time to decline or stop participation, withdraw consent from participation, or refuse to answer any questions without penalty or loss of benefits from which you are allowed from this research. If you choose to stop your participation in this research, all information obtained will not be used in this research project.

Questions about the Study

If you have any questions about the research now, please ask. If you have questions later about the research, you may contact Debbie Evans-Rogers by phone: (281) 480-6755 or email: drogers187@att.net. If you have questions regarding your child's rights as a human subject and participant in this study, you may call the Institutional Review Board at Rocky Mountain University of Health Professions. The telephone number of the IRB Committee is (443) 926-6243. You may also write to the committee at irb@rmuohp.edu or fax (801) 734-6771.

Consent to Participate

The Institutional Review Board Committee at Rocky Mountain University of Health Professions has approved this consent form as signified by the Committee's stamp. This consent form must be reviewed at least once every year and expires one year from the approval date indicated on the stamp.

______________________________	__________	________________________	________
Printed name of Investigator	**Date**	**Signature of Investigator**	**Date**

Parent's Statement

This study has been explained to me. I agree to allow my child to take part in this research. I have had a chance to ask questions. If I have questions later about the research, I can ask one of the researchers listed above. If I have questions about my child's rights as a research subject, I can call the Rocky Mountain University of Health Professions Institutional Review Board Committee at (443) 926-6243. My signature also indicates that I can change my mind and withdraw my consent to allow my child to participate at any time without penalty. I will receive a copy of this consent form.

____
Printed name of Participant

______________________________ ________________________________ _____
Printed name of Parent/Legal Guardian Signature of Parent/Legal Guardian Date

Please initial the appropriate line.

_____I consent to have my child videotaped and photographed for this study and for further educational purposes for training pediatric therapists in the treatment of children with neuromotor disabilities, and kept indefinitely, for teaching purposes.
_____I wish to have my child's face masked on any videotapes or photographs used for this study or instructional purposes.
_____I do not consent to have my child videotaped and photographed for this study and for further educational purposes for training pediatric therapists in the treatment of children with neuromotor disabilities.

Rocky Mountain University of Health Professions
Consent to Participate as a Research Subject
<u>Adult NDT Participant</u>

Short-term, Intensive Neurodevelopmental Treatment (NDT) Program Experiences of Parents and their Children with Disabilities

Investigators:

Debbie Evans-Rogers, PT, MS, PCS, Doctoral Candidate for Doctor of Science in Pediatrics
Rocky Mountain University of Health Professions-Provo, Utah
(832) 480-6755

Dr. Jane Sweeney, PT, PhD, PCS, FAPTA
Professor and Graduate Program Director-School of Rehabilitation Sciences
Rocky Mountain University of Health Professions-Provo, Utah
(253) 265-3866

Dr. Patricia Holden-Huchton, RN, DSN, CNE
Dean and Professor, College of Nursing
Texas Woman's University
(940) 898-3515

Dr. Pamela Mullens, PT, PhD
Coordinator Instructor for Neurodevelopmental Treatment-Pediatric and Adult patients
Private practice-Seattle, Washington
(206) 524-1743

Investigator's Statement

We are asking you to be in research study. The purpose of this consent form is to give you information you will need to help you decide whether to participate in the study or not. Please read the consent form very carefully. You may ask questions about the purpose of the research, what we would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this consent form that is not clear. When we have answered all you questions, you can decide if you want to be in the study or not. This process is called 'informed consent.' We will give you a copy of this form for you records.

Purpose of the Study

The purpose of this research study is to explore parents' perspectives about their child's participation in an intensive 5-10 days, 2-4 hours a day, neurodevelopmental treatment (NDT) program, and to examine how NDT treatment affects movement and function in the individual attending the NDT program. It is conducted by Debbie Evans-Rogers, a doctoral candidate in the Pediatric Science program at Rocky Mountain University of Health Professions (RMUoHP). You were selected because you will be participating in the NDT handling intensive program through Partners for Progress.

Description of the Study

This study will incorporate both using interviews which is called qualitative research, and collecting numerical data which is called quantitative research. The anticipated number of participants for this research is twenty. Both male and female individuals aged one to twenty one years old with a disabling condition participating in the five or ten day intensive program will be recruited for this study. To be eligible for this research study: 1. Child or adult must be age one to twenty one with a diagnosis of CP or other neuromotor condition affecting their participation and functional abilities;
2. Child or adult must participate in 70% of the five or ten day intensive program
The total duration commitment will be one week from July 12-16, 2010; or two weeks from July 12-16, and July 19-23, 2010; or one week from October 25-29. 2010. The total commitment time for the handling intensive program is two to four hours/day with a weekly commitment of 10-20 hours. A first evaluation or pretest using the COPM and the GAS (requiring a maximum time of 25 minutes), 1-2 daily, two hour intervention sessions, and a second post-test using the COPM and GAS of 25 minute duration after each week of intervention will be scheduled at a time convenient for you.
Videotapes and pictures are customarily taken of individuals during the therapy sessions of the intensive program with your consent. For purposes of this study, videotaping and photographs of you during therapy sessions would be requested to included with this study as well.
The location of the research study will be at the St. Dominic Catholic Church in Brookfield, Wisconsin or the Gethsemane United Methodist Church in Pewaukee, Wisconsin where the Partners for Progress handling intensive programs are performed.

The study procedures for adult participant in the intensive program will include:
1. You will be asked to participate in a short questionnaire prior to and after each week of the intensive program about your ability to perform everyday activities called the Canadian Occupational Performance Measure (COPM). A rating on the scale of 1-10 for performance, importance and satisfaction of performance will be scored with your assistance.
2. You will be evaluated before and after each week of the intensive NDT program using a functional outcome measure, Goal Attainment Scaling (GAS). You will be asked to assist with goal writing for the GAS.

What is Experimental in This Study

None of the intervention procedures or questionnaires used in this study are experimental in nature. The only experimental aspect of this study is the gathering of the information for the purpose of analysis.

Potential Risks, Stress, or Discomfort

There are minimal risks to you associated with your participation with this research study. Trained therapists familiar with GAS and COPM will assist you with ideas for goals if needed and scoring procedures. The greatest inconvenience to you will be your participation in the daily intervention sessions, requiring planning from you to attend the majority of the sessions.

Potential Benefits from Participation

I cannot guarantee, however, that you will receive any known benefits from participating in this study. The benefits of participating in this study on the intensive program may be that you get stronger and are able to improve with functional abilities. By participating in the this research study, other families and individuals with special needs may benefit from the knowledge gained regarding an intensive Neurodevelopmental program.

Alternate Methods of Treatment

You may choose not to participate in this intensive NDT program or in this study. You may continue with your usual care and therapy, and participate in this intensive program even if not participating in this research.

Confidentiality

Strict confidentiality will be maintained to the extent allowed by law. Individual identifying information obtained from this research study will be kept confidential.
Where possible, all identifying references of each participant will be removed and Replaced by an alphabetical and numeric code identifier. All data pertaining to your information will be stored in a locked file only accessible to the investigator. The master list linking the codes to you will be kept in a separate locked file cabinet. Only the researcher involved in the study, the transcriptionist, and the instructors at RMU will have access to the data collected. Additional investigators and transcriptionist will be trained in all confidentiality procedures and policies of the study. All data pertaining to this research study will be retained for 7 years as recommended by RMUoHP IRB policy. The data may be presented at conferences, courses, or published but no personal identifying information will be released. Videotapes will be protected in a locked cabinet. You will be asked to consent to use the videotapes for educational purposes for training pediatric therapists in the treatment of children with neuromotor disabilities, and kept indefinitely, with your permission. You can have your face masked for confidentiality purposes. If you agree, the videotapes will be kept indefinitely for educational and professional presentations and not for commercial use. If you do not agree, the tapes will be erased in seven years and will not be used for educational or professional purposes. If you have provided consent of photographs, if this research is accepted for publication, you will be asked and consent will be obtained before any photograph may be published in the research article and/or poster presentation.

Incentives to Participate

Upon completion of this study, a small token of thanks by means of a gift card consisting of $10.00 from Starbuck's will be provided to all families participating in the study.

Costs and /or Compensation for Participation

There will be no costs incurred to the participant and parents to participate in this research study (other than the cost required by Partners of Progress for the NDT intensive program).

Voluntary Nature of Participation

Participation in this study is strictly voluntary. Your choice of whether or not to participate will not influence your future relations with Rocky Mountain University of Health Professions or Partners for Progress. If you decide to participate, you are free to withdraw your consent and to stop your participation at any time without penalty or loss of benefits to which you are allowed.

You have the right at any time to decline or stop participation, withdraw consent from participation, or refuse to answer any questions without penalty or loss of benefits from which you are allowed from this research. If you choose to stop your participation in this research, all information obtained will not be used in this research project.

Questions about the Study

If you have any questions about the research now, please ask. If you have questions later about the research, you may contact Debbie Evans-Rogers by phone: (281) 480-6755 or by email: drogers187@att.net. If you have questions regarding your rights as a human subject and participant in this study, you may call the Institutional Review Board at Rocky Mountain University of Health Professions. The telephone number of the IRB Committee is (443) 926-6243. You may also write to the committee at irb@rmuohp.edu or fax (801) 734-6771.

Consent to Participate

The Institutional Review Board Committee at Rocky Mountain University of Health Professions has approved this consent form as signified by the Committee's stamp. This consent form must be reviewed at least once every year and expires one year from the approval date indicated on the stamp.

______________________	________	______________________	________
Printed name of Investigator	**Date**	**Signature of Investigator**	**Date**

Subject's Statement

This study has been explained to me. I volunteer to take part in this research. I have had a chance to ask questions. If I have questions later about the research, I can ask one of the researchers listed above. If I have questions about my rights as a research subject, I can call the Rocky Mountain University of Health Professions Institutional Review Board Committee at (443) 926-6243. My signature also indicates that I can change my mind and withdraw my consent to allow my child to participate at any time without penalty. I will receive a copy of this consent form.

I understand that my signature on this form constitutes my informed consent to act as a subject in this research project. Participation in this study is entirely voluntary. No medical service or compensation is provided to subjects by the university as a result of injury from participation in this research.

Please initial the appropriate box.

_____1. I agree to to be videotaped, and to have my picture taken/used for study and presentation purposes.
_____2. I agree to allow my picture to be taken for the study and presentation purposes but require that my face be masked.
_____3. I do not agree to to be videotaped, and to have my picture taken/used for study and presentation purposes.

______________________	________	______________________	________
Printed name of Participant	**Date**	**Signature of Participant**	**Date**

Rocky Mountain University of Health Professions
Assent to Participate-Age 9 and above

Short-term, Intensive Neurodevelopmental Treatment (NDT) Program Experiences of Parents and their Children with Disabilities

My name is Debbie Evans-Rogers. You are being asked to be part of a research study on therapy experiences using a hands-on therapy called neurodevelopmental treatment or NDT. I am trying to learn more about if doing therapy for four hours a day for one to two weeks helps you better than doing therapy in a more typical way such as every week for one hour. If you agree to be in this study, you will be asked to attend your therapy sessions every day. The biggest part of this study involves participating in the therapy program and your parents may be asked questions about how the program has affected you and your family.

You will be evaluated on how you are accomplishing activities before and after each week of this therapy program. Your therapists will be using two particular scales called Goal Attainment Scaling (GAS) and the Canadian Occupational Performance Measure (COPM). Both you and your parents will be asked to assist with writing goals or activities using these scales. There are minimal risks in being a part of this research study. I cannot guarantee, however, that you will receive any benefits from being a part of this study. The intensive program may make you stronger or help you with getting better at moving. Please talk to your parents about this study before you decide to participate. We will also ask your parents if it is all right with them for you to take part in this study. If your parents say that you can be in the study, you can still decide to not participate. Taking part in this study is up to you. No one will be upset if you don't want to participate. If you decide to be a part of this study, please remember you can always change your mind and stop participating any time you want to. You can ask me questions that you have about this study and I will try to answer them for you. If you have questions that you think of later, you can call me at (281) 480-6755 or email me at drogers187@att.net.

Please mark one of the choices below to tell us what you want to do:

____No, I do NOT want to be in this project   ____Yes, I want to be in this project

Please mark if the following is okay:
____It is okay for me to be videotaped.
____It is okay for me to have pictures taken of me.

Print your name here (Participant)	Date	Sign/Write you name here (Participant)	Date
Printed name of Investigator	Date	Signature of Principal Investigator	Date

Rocky Mountain University of Health Professions
Assent to Participate-Younger Children

Short-term, Intensive Neurodevelopmental Treatment (NDT) Program Experiences of Parents and their Children with Disabilities

Hi! My name is Debbie. I am in school. I am trying to learn more about therapy and helping kids. You are going to be coming here for therapy for this week (and maybe next week). While you are here, will you help me learn about your therapy? I will be writing down notes, asking questions, and writing goals with you and your caretaker (e.g. mom and dad). I may also have a longer talk with your parents.

Nothing will hurt and the goals I will be writing are using two guides called Goal Attainment Scaling and the Canadian Occupational Performance Measure.

Even if you decide not to be a part of this study, you can still come to the intensive program and receive therapy. It will not affect your relationship with the people putting on the intensive program.

If you do decide to be part of helping me with this study, at any time you can decide to stop and not help anymore. This is absolutely okay.

I may be taking pictures and videotaping as part of the study during the intensive program. I wanted to ask if this was okay with you too if you decide to help with the study.

Can you make a mark if it is okay or not okay with you to help with my school work?

This means it is okay.	This means it is not okay.
YES______________	**NO_______________**

Can you make a mark if it is okay or not okay with you for me to take pictures?

This means it is okay.	This means it is not okay.
YES______________	**NO_______________**

Can you make a mark if it is okay or not okay with you for me to videotape?

This means it is okay.	This means it is not okay.
YES______________	**NO_______________**

____
Print your name here (Participant)

_________________________	______	________________________	_______
Printed name of Investigator	Date	Signature of Principal Investigator	Date

Rocky Mountain University of Health Professions
Waiver of Documentation of Assent To Participate in a Clinical Research Project

Short-term, Intensive Neurodevelopmental Treatment (NDT) Program Experiences of Parents and their Children with Disabilities

Principal Investigator (PI): Debbie Evans-Rogers, PT, MS, PCS

PI Statement:

A waiver of assent will be implemented when a child is under the chronological age of 7, or as deemed by parent/guardian the child's cognitive ability is at a level unable to understand the assent form.

The assent of (________________________________) is waived due to:
Name of child

the age of the child ☐

cognitive ability of the child to understand assent form ☐

________________________________ ________________________________
Printed Name of Parent/Guardian Signature of Parent/Guardian

Child's Name:________________________________ DOB:____________________

Appendix J: Recruitment Form Letter (letter of participation)

To Families participating in the Partners for Progress Intensive Program,

Thank you for your interest in the intensive NDT program! I am Debbie Evans-Rogers, a graduate student at Rocky Mountain University of Health Professions. I am very interested in the Partners for Progress intensive program and I am hoping to collect participant data for my graduate research study entitled: "Short-term Intensive Neurodevelopmental Treatment Program Experiences of Parents and their Children with Disabilities."

I am hoping to interview parents regarding their experiences with the program. The interview would take about one hour of your time. I would also like to collect data on goals your child may accomplish during and after each week of intervention (some of you may be participating in one week of the intensive program, and some of you may be participating in two weeks of the intensive program). These goals would be set in collaboration with you and your therapists and the time to set these goals would be during the already scheduled times for intervention of your child.

I am hoping to interview a maximum of 20 families and will compensate families with a $10 gift card from Starbucks for taking the time to assist with this research. If you are interested in volunteering, you can let Partners for Progress know (Linda Kliebhan or Rona Alexander) when they call families participating in the intensive program. Once I am notified you are interested in participating in the study, I will send the consent form for you (as a participant to be interviewed), a parental permission form for your child (as a participant to assist with data planned to be collected in the form of goals after each week of intervention) and an assent form for your child (if applicable) to look over. You can call me at any time with questions-832 277-0209 or email me at drogers187@att.net.

I want to thank you for your consideration for my research. Your decision to participate or not participate in this project will not affect your relationship or participation in Partners for Progress. Thank you for this opportunity and I am looking forward to meeting with you.

Debbie Evans-Rogers, PT, MS, PCS

Appendix K: Table of NDT Studies

Table 2.4: Summary of Recent Clinical Studies (1999-2011) indicating significant differences after Neurodevelopmental intervention: Level of evidence, Intervention and Results

Study	**Design**	**Level of Evidence**	**Subjects N=**	**Observation/Intervention**	**Intervention Provided by**	**Outcome Measures**	**Results**
Trahan et al., 1999	Before and after case series (longitudinal design)	IV	50 Age: 12-79 months	45 minutes of PT twice a week using NDT (Evaluated at baseline, 4 and 8 months)	18 Physical therapists	GMFM	P<0.001 Significant improvements were made in gross motor performance at 4 and 8 months. (Dx: >diplegia)
Adams et al., 2000	Before and after case series (pretest-posttest) design	III quasi-experimental	40 (29 independent ambulators, 11 with walking aids) Dx: CP Age: 2-10 years	6 week NDT treatment course practicum (1 hour of treatment 2x/week) Treatment focus: facilitating active movements, inhibiting unwanted patterns and stimulating weak muscle groups e.g. for ambulation	Two therapist treatment team: physical therapist and another PT, OT or SLP	Pedographs (12 sets of footprints) height, TGMRD -test of Gross Motor and Reflex Development	P<0.05 Improvements for stride and step length, foot angle and velocity were noted with all groups.(dx: spastic diplegia made most significant changes). Base of support and cadence demonstrated changes but were not significant statistically.
Kerem et al., 2001	Before and after case series (pretest-posttest) design	III quasi-experimental	34 Dx: Spastic Diplegia Age: 36-82 months	5 days/week NDT Intervention for both groups for 3 months; the experimental group also wore Johnstone pressure splints bilaterally on legs and arms for 20 minutes during intervention	PTs in Pediatric Rehabilitation Department in Turkey-unclear if therapists had specialized training in NDT	ROM (via goniometer), Modified Ashworth Scale (MAS), somatosensory evoked potentials (SEP) of Posterior tibial nerve	In both groups, statistically significant (P<.01) improvement in ROM; MAS scores and SEP were improved in both groups and statistically significantly higher in the treatment group (p<.05)

Study	**Design**	**Level of Evidence**	**Subjects N=**	**Observa-tion/Inter-vention**	**Intervention Provided by**	**Outcome Measures**	**Results**
Trahan and Malouin, 2002	Multiple-baseline single subject design	II	5 Dx: severe CP (GMFCS Levels IV and V) Age: 10-37 months	4 times/week NDT, 45 minute sessions for four weeks as compared to 8 weeks without therapy	Physical therapist using NDT (unclear if PT had specialized training)	GMFM	P<.05; statistically significant improvements in the GMFM scores of 3 of the 5 children with the more intensive, intermittent therapy regimen with all 5 children showing improved GMFM scores
Kerem and Livanelioglu, 2002	Case study over 18 months	IV	489 Dx: CP Age: Mean ages given 10-30 months	Exercise program *("based on NDT" and given over 3 day period with F/U every 3 months)	Physical therapists (initially for evaluation) and parents to do exercises at home	GMFM and ambulation evaluation using observation	P<0.05 Improvement was reported with > significance in the "early" (< 12 month) vs. "late"(> 12 month) exercise group
Knox and Evans, 2002	Before and after case series (Repeated measure design)	IV	15 Dx: CP Age: 2-12 years	Bobath/NDT therapy with sessions lasting 75 minutes and attendance min 3x/week. Testing at 6-wkly intervals.	Physical therapists (2 were Bobath tutors, and 3 in-training to tutor)	GMFM and PEDI	P<0.05 Significant improvement in scores (before and after therapy) seen in GMFM total scores and PEDI self care skills
Tsorlakis et al., 2004	Randomized control trial (RCT)-2 groups	II	34 Dx: CP Age: 3-14 years	Group A: NDT 2x/week Group B: NDT 5x/week For a total of 16 weeks	Physical therapists	GMFM	P<0.05 Significant improvement was seen in scores on the GMFM for both groups, with the intensive NDT intervention having a greater effect.

Study	**Design**	**Level of Evidence**	**Subjects N=**	**Observation/Intervention**	**Intervention Provided by**	**Outcome Measures**	**Results**
Bar-Heim et al., 2006	Randomized block design	II	24 Dx: CP Age: 6-12 years	Adeli Suit Treatment (AST) and NDT. Treatment was for 4 weeks/ 20 sessions (2 hrs/day, 5 days/wk)	Physical therapists specialized in AST and in NDT	GMFM-66 and Mechanical Efficiency Index (EI_{HB})	P<.05 Both groups had significant improvements in motor abilities (supporting intensity of Rx). AST group had improved EI_{HB} when compared to NDT group.
Arndt et al., 2008	Repeated measures randomized block design	II	10 Infants identified with postural and movement dysfunction Age: 4-12 months	2 Groups: one receiving an infant NDT based sequence trunk coactivation (STA) protocol; one receiving parent-infant play (PIP) protocol Treatment was for 10 one hour sessions over 15 days for both groups	STA group received intervention from pediatric NDT trained therapists, PIP group received enriched PIP activities by parents with guidance from a child life specialist	GMFM	P<.05 The NDT-based group made significantly more progress when compared to the control play group
Bierman, 2009	Single case report	IV	1 Age: 5 1/2 Dx: Spastic quadriplegia and dystonia	PT 3-4 hours/day in conjunction with OT and Speech, 1 hour/3-4x a week, 4-6 hrs/week aquatic therapy	Expert NDT instructor	GMFM	GMFCS Level improved from a Level 5 to Level 3; 33% increase of GMFM scores, improvements in multiple system impairments, posture/movement, impairment and functional independence

Not- Supportive Findings

Study	**Design**	**Level of Evidence**	**Subjects N=**	**Observation/ Intervention**	**Intervention Provided by**	**Outcome Measures**	**Results**
Mahoney et al., 2001	Case study over one year (pretest-posttest)	IV	50 (27 with diagnosis of Down Syndrome, 23 with diagnosis of CP) Age: Mean age of 13.9-14.3 months	NDT and Developmental Skills (Receiving 12 months of intervention)	Early Interventionists or Physical Therapists	Bayley Scale of Mental Development, Peabody Developmental Motor Scales, Toddler, Infant Motor Evaluation (TIME), & videotaping to analyze quality of movement	No significant differences were found between groups. Significant differences in development were found with higher intensity service groups.

Other Significant NDT Studies before 1999 (both positive and negative findings)

Study	Design	Level of Evidence	Subjects N=	Observation/ Intervention	Intervention Provided by	Outcome Measures	Results
Jonsdottir et al., 1997 (Fetters and Kluzik 1990)	Multiple crossover trial	II (assuming randomization into 2 groups of practice and NDT)	8 Dx: Spastic Quadriplegic CP Age: 10-15 years	5 days of NDT treatment, and 5 days with practice of reaching tasks, each 35 minutes/day	2 Physical therapists; an NDT trained therapist providing NDT and another therapist providing repeated reaching practice	Modified Posture Assessment Scale (PAS), kinematic analysis and videography using WATSMART (Waterloo Spatial Motion Analysis and Recording Technique)	No difference in head/shoulder displacement or PAS scores with NDT or practice. P<0.05 NDT over practice was more effective in improving postural alignment (when extreme scores were excluded)
Law et al., 1997	Randomized cross-over design	II	50 Dx: CP Age: 18 months to 4 years	Treatment Group 1: Intensive NDT and Casting Treatment Group 2: regular OT (each intervention was for 4 months)	Occupational Therapists	PFMS (Peabody Fine Motor Scales) for hand function, QUEST (Quality of UE Skill Test) for quality of movement, COPM for parent's perceptions of hand functions	No significant difference was found in hand function, quality of UE movement, or parents perceptions of hand functions between the 2 treatment groups.
Girolami et al., 1994	Randomized, controlled clinical trial	II	9 (treatment control group) 10 (preterm control group) 8 (term infants receiving no intervention)	14-28 treatment sessions during period of 7-17 days. Infants were randomized assigned to either treatment or control groups. Treatment received was NDT protocol: twice daily for 12-15 minutes	PT-certified NDT instructor	Neonatal Behavioral Assessment Scale, supplemental motor test for assessment of postural control	P<0.01 NDT-based intervention was effective in improving postural control in infants born prematurely

Study	Design	Level of Evidence	Subjects N=	Observation/ Intervention	Intervention Provided by	Outcome Measures	Results
DeGangi, 1994 (Part 1 & 2)	Case study	IV	6 Age: 1-6 years Dx: CP (spastic quadriplegia, diplegia, hemiplegia, and hypotonia)	2x/week, one hour sessions for eight weeks with program consisting of NDT	OT trained in NDT	Peabody Developmental Motor Scales and observations of qualitative movement from Test of Motor and Neurological Functions	Progress was made by each of the cases in qualitative movement and postural findings using pre- and post-test measures. Parents noted improvements in movement and play skills.
Mayo, 1991	Randomized, controlled clinical trial	II	17 (intensive group) 12 (basic group) Mean Age: 9-12 months	Intensive (weekly) and basic (monthly) groups based on NDT principles	Physical therapist trained in NDT	Seven aspects of motor development were assessed: reflex activity, postural reactions, gross motor abilities, fine motor abilities, Bayley (mental scale), abnormal movement scale, activities of daily living	P=.001 Intensive treatment group (receiving weekly therapy) responded better compared to the basic (monthly) group. Intensive NDT was found to be superior to the basic regimen of a home program
Lilly and Powell, 1990	Single-subject design (multiple crossover trial)	II	2 Dx: CP Age: 27 and 32 months	12 weeks of NDT followed by play, or vice versa	Occupational therapist trained in NDT for occupational therapy, and OT student for play sessions	Dressing skills- tested both pre and post of each therapy session	No significant differences were found with NDT or play
Sharkey et al., 1990	Prospective Case study	IV	100 (50 children referred prior to 9 months of age; the early group, and 50 children referred after 9 months of age; the late group)	Treatment techniques were based on NDT principles developed by the Bobaths	Therapists with a home follow-up program requiring parental involvement	Early Intervention Developmental Profile (EIDP)- implemented at initial evaluation and after 6 months of intervention	Developmental outcomes at 18 mo. of age were improved for the infants receiving earlier intervention (prior to 9 mo. of age) as compared to the infants receiving later intervention (after 9 mo.)

Study	**Design**	**Level of Evidence**	**Subjects N=**	**Observation/Intervention**	**Intervention Provided by**	**Outcome Measures**	**Results**
Palmer et al., 1988	Randomized controlled clinical trial	I	47 (25 in Group A, 22 in Group B) Dx: mild to severe spastic diplegia Age: 12-19 months	Group A: 12 months of NDT physical therapy Group B: 6 months of NDT physical therapy proceeded by 6 months of infant stimulation	Physical therapists provided PT and child development specialists provided infant stimulation using a Learninggames program	Motor and mental quotients using Bayley Scales	The routine use of NDT physical therapy offered no advantage over infant stimulation.
Herndon et al., 1987	Before and after case study (pretest-posttest design)	IV	12 Dx: mild, moderate and severe CP Age: 6-14	Videotaped before and after NDT course	6 evaluators-4 physical therapists (2 with NDT training, 2 without) and 2 orthopedic surgeons	Range of motion measurements and movement pattern differences	No significant changes were noted after 6 weeks of NDT therapy
DeGangi et al., 1983	Single subject design	IV	4 Dx: CP mild to moderate hemiplegia, spastic quadriplegia, diplegia, hypotonia Age: 10-22 months	2x/week 8 treatment sessions total (due to illness) over a 5 week time period 25 minutes of NDT 25 minutes of play	2 PTs and 1 OT certified in NDT	Videotaped testing sessions consisting of 3-5 items picked by therapists	No statistically significant findings supporting NDT over non-specific play
Harris et al., 1981	Randomized controlled clinical trial	II	20 Dx: Down Syndrome Age: 2-21 months	3x weekly, 40 minute sessions for nine-week period 2 groups: one treated with NDT, one group continued weekly involvement in an infant learning program	2 Physical Therapists	Bayley Scales of Infant Development and the Peabody Developmental Motor Scales; four individual therapy objectives	No significant difference was found between the 2 groups; a statistically significant difference in favor of the NDT group was found for attainment of individual treatment objectives

Study	**Design**	**Level of Evidence**	**Subjects N=**	**Observation/ Intervention**	**Intervention Provided by**	**Outcome Measures**	**Results**
Scherzer et al., 1976	Randomized controlled clinical trial with double-blinding	II	22 Dx: CP Mild to severe (athetosis, spastic quadriplegia, hemiplegia, ataxia) Age: 5-17 months	2x weekly up to the age of 2 years. Control group received passive ROM exercises; Experimental group received a "neurophysiological PT approach" combining Rood, Knott and Bobath therapy	2 Physical therapists	Medical and physical therapy evaluations observing changes in motor status, social maturation, and home management by parents	Experimental group consistently showed greater improvement (% of change) for each response category with a strong trend of positive changes with higher intelligence
Carlsen, 1975	Randomized controlled clinical trial	II	12 Dx: CP Mild to moderate spastic quadriplegia, diplegia, hemiplegia and athetosis Age: 1-5 years	2x weekly for one-hour sessions; 6 week duration 2 groups: Group I- facilitation group with a program as defined by the Bobaths, Rood, and Ayres consisting of postural stability and sensory organization Group 2- functional group consisting of positioning and self-care skills	OTs	Denver Developmental Screening Test (DDST) and Bayley Motor Development Scale (BMS)	Children in Group 1 (facilitation group) as compared to Group 2 (functional group) achieved > improvement in all areas of development (p<.05). Treatment was suggested to concentrate on gross sensorimotor activities.

CURRICULUM VITAE

Debbie Evans-Rogers, PT, MS, PCS
838 Maplewood Falls Ct. Houston, Texas 77062
(281) 480-6382
drogers187@att.net

Education:

Post-graduate: enrolled in PhD program (3/07-present)
Degree: Doctor of Philosophy, Pediatric Science
Rocky Mountain University of Health Professions; Provo, Utah
Didactics completed: May 2009 GPA: 3.89

Graduate degree: Master of Science (MS) in Special Education
(Preschool handicapped specialization)
Old Dominion University-Norfolk, Virginia
Graduating with honors: 4.0 GPA May 1991

Undergraduate degree: Bachelor of Science (BS) in Physical Therapy
University of Missouri-Columbia
Graduating with honors (Cum Laude)-May 1985

Licensure: Executive Council of Physical Therapy and Occupational Therapy Examiners Tx PT License No. 1107886; Wisconsin PT License No. 11556-24

Clinical Specialist: APTA Pediatric Clinical Specialist (1996 to present)

Professional Work Experience:

Pediatric Physical Therapist and Clinical Instructor
University of Texas Medical Branch, ECI-Launch
301 University Blvd. Galveston, TX 77555-1025
11/96 to present

Owner-Pediatric Private Practice
Pediatric Physical Therapy of Clear Lake
Houston, Texas
March 1997-1999

Pediatric Physical Therapist
St. Agnes Children’s Rehabilitation Center
Carmel, New York
11/95-8/96

Sole Proprietor: Pediatric Physical Therapist
Self-employed therapist treating in home
Virginia Beach, Virginia
6/91-7/95

Pediatric Physical Therapist
Chesapeake Infant Intervention Program
Chesapeake, Virginia
8/92-10/95

Pediatric Physical Therapist and Clinical Instructor
Virginia Beach School System
Virginia Beach, Virginia
8/89-6/94

Pediatric Physical Therapist
Sentara Home Health Services
Norfolk, Virginia
6/90-4/92

Inpatient and Clinic Outpatient Pediatric Physical Therapist
Children's Hospital of the Kings Daughters
Norfolk, Virginia
2/87-5/89

Pediatric Physical Therapist
Ada Wilson Hospital of Physical Medicine and Rehabilitation
Corpus Christi, Texas
9/85-12/86

Teaching Experience:

NDTA Pediatric Instructor (2010 to present)

NDTA Pediatric Handling: Basics and Beyond
Winter Pediatrics
Houston, Texas Feb 19-20, 2011

Improving Gait and Mobility for
Pediatric Clients: A Blend of EBP and Direct
Handling using NDT
Houston, Texas October 8-9, 2010

Served as Lab Assistant for Linda Kliebhan-NDT
Approach to Treatment of the Infant and Young
Child-Texas Children's Hospital, Houston, Tx. 11/13/09-11/15/09

-

Served as Lab Assistant for Lois Bly-NDT Approach to Infant Treatment
Neurodevelopmental Treatment Services, Pearland, Tx. 8/19/08-8/23/08

Teaching as full-time PT Instructor Candidate
NDT Certificate Course in the Management and Treatment of
Children with Cerebral Palsy and Other Neuro-Muscular Disorders
The Care, Group, Houston, Tx., 3/08-10/08

Clinical Instructor for Master's Program PT Students
Regis University-Jinotepe, Nicaragua 11/2000
Adjunct Faculty for Master's PT Program
Old Dominion University-Norfolk, Virginia 9/92-10/95

Adjunct Professor for PTA Students
Tidewater Community College-Virginia Beach, Va. Jan-May 1995

PT Instructor for Romanian Therapists
Operation Smile-Hirlau, Romania 9/93-10/93

Professional Certificates/Training:

NDTA Pediatric PT Instructor: 2010-present

NDT/Bobath Certificate Course in the Management and Treatment and Treatment of Children with Cerebral Palsy and Other Neuro-Muscular Disorders-1988

Board-Certified Clinical Specialist in Pediatric Therapy (PCS)-1996, recertified in 2005

NDT Advanced Baby Course Training- 1988

Sensory Integration and Praxis Test (SIPT) Certified- 1998

Professional Memberships:

American Physical Therapy Association (APTA)
Section on Pediatrics of the APTA
Texas Physical Therapy Association (TPTA)
Neuro-Developmental Treatment Association (NDTA)

Committee Responsibilities: National Level

NDTA Past President (appointed)-2004-2005
NDTA Director of Regions-1997-2000
NDTA Finance Committee-97-99, 04-05

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Honors:
Chancellor’s Leadership Scholarship-1985
Rotary Club Award-Nicaragua-11/00
Regi Boehme Scholarship-2008

Research:
Thesis: *The Effects of Orthotic Management on Gross Motor Skills of Young Children with Motor Impairment 5/91*

Attitudes of Special Educators toward Physical and Occupational Therapy in the Public School System. TASH Conference 1991

Publications:
Goal Attainment Scaling: Overview and Insights with NDT Research; NDTA Network: Feb/March 2011

Poster Presentation: *Examining NDT with increased intensity for a child with spastic quadriplegia CP and dystonia: A Case Report*. NDTA Annual Conference May 2011

Poster Presentation: *Effects of the Interactive Metronome on Motor Skills and Functional Performance in an Eight Year old Boy: A Case Report.* Section of Pediatrics Annual Conference 1/2010

Debbie Evans-Rogers has been a pediatric physical therapist for 26 years. She has worked in a variety of settings including her own private practice, the school system, children’s hospitals (both inpatient and outpatient facilities), home health, and many early intervention programs. She obtained her Master’s degree in special education (with a preschool handicap emphasis) in 1991 from Old Dominion University (ODU) in Norfolk, Virginia. She taught Master’s-level physical therapy students as an adjunct professor at ODU for three years. She received her pediatric certified specialty from the APTA in 1996, and was recertified in 2006. She has traveled to Romania, Nicaragua, and India assisting both in-country therapists and PT students. She is a pediatric Neurodevelopmental Treatment (NDT) instructor and has been active in the NDTA since 1987 prior to her initial 8 week basic pediatric course. She received her NDT Advanced Baby treatment certification in 1998. She has been involved at the regional level of the NDTA serving as Region 9 chair and Region 5 co-chair. She has served on the Board of Directors twice, once as the Director of Regions, and once as the Past-President (appointed). She enrolled in Rocky Mountain University of Health Professions in Provo, Utah pursuing her Doctor of Philosophy degree in 2007.

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