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PARENT AND THERAPIST PERCEPTIONS OF SENSORY BASED STRATEGIES
USED BY OCCUPATIONAL THERAPISTS IN FAMILY-CENTERED EARLY
INTERVENTION PRACTICE

A thesis submitted in partial fulfillment of the requirements for the degree of Master of
Science in Occupational Therapy at Virginia Commonwealth University

by

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ACKNOWLEDGEMENT

This has been a long and arduous process and without the assistance of numerous individuals along the way, this project would never have come to its fruition. My advisors, Dianne Koontz Lowman, Dianne Simons and Jayne Shephard spent countless hours reading and dissecting what I have written and showered me with encouragement and praise along the way to keep me going. Through coursework, Dianne Simons and Dianne Koontz Lowman also gave me the tools and knowledge of both occupational therapy theory and research practice to complete such a project.

Several occupational therapy and early intervention practitioners were key in providing support and assistance in helping me to find participants for this study. Pam Park, an occupational therapist, used her influence to help me find other therapists and parents to interview in the county where she provides intervention. Her supervisor, Susan Sigler, allowed me to contact her therapists and provided guidance in how to contact parents in her jurisdiction. Jayne Shephard assisted with finding therapists in a city program in close proximity to Virginia Commonwealth University and Audrey Kane, a therapist in this program encouraged one of her colleagues to participate in the study as well. Without the support and encouragement of each of these individuals, this study would never have been launched.

Most importantly, the support and endless sacrifices of my husband, Ogden, and son, Gordon has been invaluable. My husband spent countless hours entertaining my son while I was toiling away at the computer wading through the mire of data that is part of a qualitative study. My son was very patient throughout this process, allowing me time to work when he would much rather have some playtime with his mother, but also letting me know when it was time to stop because it was his turn. Without all of these people, as well as my coworkers and clients who supplied me with support and encouragement along the way, this project would never have reached its completion.

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ABSTRACT

PARENT AND THERAPIST PERCEPTIONS OF SENSORY BASED STRATEGIES USED BY OCCUPATIONAL THERAPISTS IN FAMILY-CENTERED EARLY INTERVENTION PRACTICE

By Juliet B. Copeland

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy at Virginia Commonwealth University.

Virginia Commonwealth University, 2006

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Assistant Professor, Department of Occupational Therapy

A qualitative approach was used to explore perceptions of parents and therapists in early intervention regarding sensory diets and their efficacy, particularly their goodness of fit within family routines and occupations. Open-ended interviews were conducted with therapist and parent participants and analysis of the data resulted in a model depicting how sensory diets became a “way of life” for families. The Sensory Diet “Way of Life” Model revealed seven themes that illustrated how occupational therapists in early intervention establish a “partnership” with parents to address a child’s needs. Once this “partnership” is established, knowledge is transferred to parents who then transform their “vision” of their child and are empowered to generalize knowledge of sensory processing and sensory diets to ever enlarging environments. Ultimately, the sensory diet became a

“way of life” for these families. Implications for the field of occupational therapy were given following the presentation of the model.

CHAPTER I: INTRODUCTION

Infancy and childhood are times of intense growth and development for children who are typically developing and for children with disabilities. When parents find that their child is not developing at a pace similar to his or her peers, they have the option of seeking resources from an early intervention program. The Individuals with Disabilities Education Act (IDEA, 2004) provides guidelines for the provision of early intervention services to children with disabilities and their families. Part C of IDEA 2004 specifically addresses services for children from birth until age three and their families, and these services are commonly referred to as early intervention services. According to IDEA 2004, early intervention services are designed to meet the needs of the family in enhancing their child's development and services are selected in collaboration with parents. The emphasis in early intervention programs is to target the parent-child relationship as a basis for helping a child to grow and develop optimally. Family-centered early intervention includes the family in the decision making process, in terms of planning, assessment and service delivery. Family-centered intervention also embraces a commitment to providing services for the whole family and not just the child. Services are guided by the family's priorities for goals and services, and offer and respect the family's choices regarding their level of participation (Murphy, Lee, Turnbull & Turbiville, 1995). IDEA 2004 states that services are provided in an environment that is

natural to a child without disabilities. IDEA 2004 defines natural environments as any home and community settings in which children without disabilities participate.

Occupational therapists, as service providers, have the role of consulting with parents and assisting them in appropriate ways to meet what the parents have identified as service needs. The key words in early intervention practice are family collaboration, consultation, and parent education (IDEA, 2004).

The family-centered practice model has involved a shift in perspective for many therapists who were educated within the paradigm of the medical model, with the therapist seen as the expert. In the past, many therapists were educated to believe that each type of therapy had a defined role delineated within the system, and therapeutic intervention involved a hands-on approach with the child. The family-centered model of practice, on the other hand, involves developing outcomes that are parent-directed, therapy that is embedded in the family routines and activities, and a transdisciplinary model of practice (Lawlor & Mattingly, 1998). Transdisciplinary practice comprises the provision of one therapy discipline as a provider to the family and inviting consultation as needed from other therapy disciplines.

Several studies polled parents in what they considered important in their early intervention practitioners (Iverson, Shimmel, Ciacera, & Prabhakar, 2003; Mahoney & Filer, 1996; McWilliam, Lang, Vandiviere, Angell, Collins, & Underdown, 1995). Parents in these studies voiced that providing support to them as parents was as important, if not more important than the hands-on therapy their child received from the therapist. These parents reported that the type of support they needed was to help them to:

find resources on child-based community service systems, develop parent networks, value the time spent with their child, and develop strategies and set goals in limit setting and discipline. Therapists have reported that addressing the mother-therapist relationship and fostering effective communication were more important in helping parents promote perceived confidence and competence as family members, than exercise programs or adaptive equipment (Washington & Schwartz, 1996).

An essential component to family-centered practice involves not only supporting parents, but also embedding this collaboration into the daily routine of family activities and occupations. The Occupational Therapy Practice Framework (AOTA, 2002) provides the structural backbone for a discussion of daily routines and occupations. The domain of occupational therapy is to focus on “engagement in occupation to support participation in context... Health is supported and maintained when individuals are able to engage in occupations and in activities that allow desired or needed participation in home, school, workplace and community life situations” (AOTA, 2002, p. 611). In early intervention practice, the family provides the context in which the child develops; therefore, therapeutic intervention must always start within this context, embedded within the family’s routines and occupations. Some family routines and occupations for a child age birth to three years consist of getting up in the morning, eating meals and snacks, getting dressed, taking a bath, playing with friends, going to the playground, running errands with his mother, attending child care and going to sleep at night. Within the OT Practice Framework, these habits, routines, and roles, as performance patterns, play a significant part in supporting successful execution of the family’s daily occupations.

Multiple studies have explored how families adapt their routines and occupations to their child with a disability (Case-Smith, 2004; Cronin, 2004; DeGrace, 2004; Larson, 1996). Adaptation to a child with a disability was described by one parent as realigning her life path to a life course of being with and doing for her child (Larson, 1996). Other parents reported that their whole family life revolved around their child with a disability and they felt they spent much of their time trying to either occupy or pacify their child to keep him in a manageable state (DeGrace, 2004). Parents identified decisions and compromises they have had to make for their child, including changes in career plans, and also described the challenge of always being there for their child (Case-Smith, 2004). Other mothers reported that they were often exhausted in their role of mother because their child did not easily conform to social standards and these mothers felt that this reflected on them. Families articulated that a deficiency in normal family routines, coupled with less than desirable family support and high child related demands, led to a lack of sense of feeling like a family or like competent parents (Cronin, 2004; DeGrace, 2004).

As occupational therapists working in early intervention, it is important to understand the factors that hinder a child's successful participation in his or her family's routines and occupations. Many children who were born prematurely or who have regulatory difficulties that interfere with their sleeping, eating and transitions from one activity to another have been found to have significant sensory processing issues (DeGangi, Porges, Sickel & Greenspan, 1993; Weiner, Long, DeGangi, Battaile, 1996). These sensory processing issues were in turn found to interfere with mother-child

bonding (DeGangi, Sickel, Kaplan, Wiener, 1997). Occupational therapists, therefore, often use a frame of reference that addresses sensory issues, called sensory integration, in their assessment and treatment of families with children with sensory processing difficulties (Bundy & Murray, 2002). Because most of the research on the sensory integration model has been conducted with older children and in a clinic setting, interpretation of this model according to these parameters is not the best fit for early intervention practice.

Occupational therapists often use different types of sensory strategies in early intervention settings because they are easily applied within the family's routines and occupations. One term, sensory diet, first described by Wilbarger and Wilbarger (1991), uses sensory strategies embedded into family routines and occupations. A sensory diet involves finding and incorporating various sensory experiences throughout the day to keep an optimal level of arousal and performance. Activities such as deep pressure touch, vestibular, or proprioceptive inputs are thought to have the most persistent effect on behavior (Wilbarger, 1995; Wilbarger & Wilbarger, 2002a, 2002b). In family-centered practice, a sensory diet is one means used by occupational therapists to create an environment for successful occupational performance in activities of daily living (ADL), play and social participation. However, no research studies have documented the efficacy of sensory diets. Various studies have examined the efficacy of specific treatment techniques often used in sensory diets, such as deep pressure, weighted vests, and pressure garments, and their effects on arousal, anxiety, attention, and self-regulation (Edelson, Edelson, Kerr & Grandin, 1999; Fertel-Daly, Bedell & Hinojosa, 2001; Neu &

Browne, 1997). Studies have also explored parent perspectives of occupational therapy using a sensory integration approach (Cohn, 2001).

According to the number of courses (Sensory Integration for Early Intervention, TheraPeeds; Practical Applications of Sensory Integration Principles, AOTA) and books (Biel and Peske's *Raising a Sensory Smart Child*; Kranowitz's *The Out of Sync Child Has Fun*) that currently exist on sensory diets, there is evidence of widespread use of sensory diets and sensory strategies in early intervention. Because of the lack of research studies documenting the efficacy of this intervention approach, it is important to examine how sensory processing issues are being addressed. Also, proponents of current early intervention practice strongly encourage that intervention strategies be embedded within the family's daily routines and occupations (Dunst, Bruder, Trivette, Hamby, Raab, & McLean, 2001; Infant and Toddler Connection of Virginia, 2003; McWilliam, 2000), but there has been a lack of research on intervention effectiveness of strategies in addressing a child's function within family routines and occupations. Occupational therapists often utilize sensory strategies to address sensory processing issues that are interfering with a child's ability to participate in his family's routines and occupations; however there has been little research into what sensory diets therapists are using and why they are using them. Examination of therapist strategies, and whether parents have found these strategies to be effective in addressing their child's sensory processing issues, particularly within family routines and occupations, would be useful. This research benefits current family-centered early intervention practice by defining the occupational therapist's role in demonstrating best practice in supporting the child within the context of his or her family.

The purpose of this research study was to explore parent and therapist perceptions of occupational therapy services in family-centered early intervention. Specifically, this study will explore how sensory processing issues are addressed within the family's routines and occupations. The guiding questions for this research were: 1. How do occupational therapists in early intervention define sensory diets? 2. What strategies are they typically using with families, and why? 3. How are families using sensory diets on a daily basis? 4. How did occupational therapy assist families in the development of these strategies? 5. How do these sensory strategies fit into the family's everyday routines and occupations? By addressing these questions, occupational therapists practicing in early intervention have begun to define what they believe constitutes best practice in early intervention services with infants and children with sensory needs or issues. In addition, families who have received occupational therapy services in early intervention described what sensory strategies were beneficial or of no value. This information benefits occupational therapists in that they will be able to provide more family-centered, efficient and effective therapy services in early intervention.

CHAPTER II: LITERATURE REVIEW

Early interventionists have been striving to provide highest quality services to families with children with disabilities since the passage of Education of the Handicapped Act Amendments in 1986 (PL 99-457). As early intervention has been redefined over the past 20 years, occupational therapists, as key team members in the provision of early intervention services, have participated in the development of high quality early intervention services. The following literature review will explore the current research related to occupational therapy practice in the present environment of family-centered early intervention. The existing laws and parameters of family-centered early intervention will be discussed along with their effects on occupational therapy practice. Routines and occupations of typical families and of those with children with disabilities will be considered within the family-centered model and current literature on the use of sensory processing techniques and sensory diets in family-centered practice will be discussed.

Family-Centered Early Intervention Practice

Current Federal Law

In Part C of the Individuals with Disabilities Education Act (IDEA, 2004), the general parameters of early intervention practice are defined as follows. Early intervention services are designed to meet the developmental needs of each child eligible

as well as the needs of the family related to enhancing the child's development. Services are selected in collaboration with parents, are provided under public supervision by qualified personnel at a facility that follows state ordained regulations, and conform to an individualized family service plan. Early intervention services must be provided in natural environments, at least to the greatest degree that fits the needs of the child. IDEA 2004 defines natural environments as any home and community settings in which children without disabilities participate. To the level that is suitable, service providers in early intervention are accountable for consulting with parents, other service providers, and representatives of appropriate community agencies to ensure that services are provided successfully. This includes guiding parents and others regarding provision of services, participating in the multidisciplinary team's assessment of a child and the child's family, and developing integrated goals and outcomes for the individualized family service plan (IDEA, 2004). Therefore, according to IDEA 2004, early intervention's emphasis is on addressing the family's needs within its own context as a basis for helping a child to grow and develop optimally.

Current Application of Federal Law in Virginia

As this study will be conducted in Virginia, a discussion of specific early intervention practice in Virginia will be presented. The current structure for early intervention practice in Virginia was put into place in 1992, when the Virginia General Assembly passed state legislation on how the infrastructure of early intervention was to be organized. Broad parameters were established at the state level to ensure implementation of Federal Part C regulations. There are currently 40 local interagency

coordinating councils (LICCs) that develop local procedures and mechanisms for implementing policies and procedures according to state and federal regulations. The Department of Mental Health, Mental Retardation, and Substance Abuse Services (DMHMRSAS) is the lead agency that administers Part C services and the LICCs to oversee and ensure Part C regulations are being implemented according to Federal law.

To be in accordance with Federal requirements, early intervention services in Virginia must be provided in natural environments to include any home or community settings where children without disabilities participate. The natural environment model is also family-centered, with the family seen as an equal participant in the early intervention process. The family is seen as the expert on the child, and the therapist is the consultant or coach who provides insights on how to help life go more smoothly in the child's and family's functional activities (Infant and Toddler Connection of Virginia, 2004). In the past four years the Infant and Toddler Connection of Virginia, the DMHMRSAS program that oversees early intervention service provision in Virginia, has provided training in the family-centered model to therapy practitioners in Virginia. These professional development trainings have included developing goals and objectives within family-centered early intervention, delivering services in natural environments, and designing services with a family-centered focus (Infant and Toddler Connection of Virginia, 2003; Virginia Babies Can't Wait, 2000).

Implications for Occupational Therapy Practice in Early Intervention

The key words identified in both federal and Virginia state guidelines (Virginia

Part C Policies and Procedures, 2000) are family collaboration, consultation, and parent education. These terms have been the subject of multiple studies in family-centered early intervention literature. The laws pertaining to IDEA 2004 have been the catalyst for a shift away from therapist as expert to therapist as collaborator. According to Lawlor and Mattingly (1998), this shift has not been easy for many therapists, and some of the dilemmas that have arisen from this change were enumerated. They explained that many therapists are educated to practice in the culture of the medical model, where the therapist is the expert, each type of therapy has a defined role delineated within the system, and therapeutic intervention involves a hands-on approach with the child. In this model, parents who do not follow the therapeutic plan may be seen as noncompliant. The family-centered model of practice, on the other hand, involves a paradigm shift from the traditional clinical therapy model. It entails developing outcomes that are parent-directed, therapy that is embedded in the family routines and activities, and a transdisciplinary model of practice where professionals share roles and responsibilities.

Family-Centered Practice

Family-centered practice is defined in a number of articles in early childhood education literature. Murphy, Lee, Turnbull and Turbiville (1995, p. 25) described family-centered services as those that “(a) include families in decision making, planning, assessment and service delivery at family, agency, and systems levels; (b) develop services for the whole family and not just the child; (c) are guided by families’ priorities for goals and services; and (d) offer and respect families’ choices regarding the level of their participation.” In 1998, McWilliam, Tocci and Harbin surveyed six special

education service providers to develop a definition of family-centeredness in the words of the service providers. The six professionals for this study were chosen from a pool of 43 service providers and were identified for the study because they most closely matched the practices and philosophies of family-centered practice. Using the Service Provider Interview Protocol developed by the researchers, they came up with seven themes, as follows. The first theme was orienting services to the whole family; service providers recognized that the well-being of the parent was just as important as the development of the child. Other themes included thinking the best about the family without passing judgment, being sensitive of parents by putting themselves in parents' shoes, being responsive and doing whatever needed to be done, treating parents as friends, and working on child-level skills within broader community activities.

McCollum & Yates (1994) illustrated a family-centered model that supported and enhanced the role of the family as competent and confident caregivers of their children. Their research model was a triadic interaction one that used the interventionist as support to the parent-child dyad in six ways: establishing a supportive context, acknowledging parent competence, focusing attention on parent competencies and actions, providing information, modeling, and making suggestions. Schultz-Krohn (1997) further elaborated on these strategies by providing three case studies that illustrated the successful application and outcomes of this approach. The three families in this study participated in an early intervention program; the author, an occupational therapist, provided services in this program. The triadic interaction model was used with each of the three families to promote efficacy in interaction skills of all family members, including siblings. The focus

in all of these interventions was on strengthening the parent-child dyad to foster skill development in the identified child.

Demonstrating the differences between a family-centered and professional-centered model is useful in further understanding family-centered practice. Dunst, Johanson, Trivette & Hamby (1991) applied a hierarchical model with families to differentiate family-centered practice from other models. Their model is summarized in Table 1.

Table 1. Types of Family-Oriented Early Intervention Programs According to Dunst (1991)

Programs	Professional Role	Family Role
Professional-centered	Professional is the expert and determines family needs	Family in deficient role and incapable of solving their own problems.
Family-allied	Professional is the expert	Families are agents of the professional and implement the professionally driven program.
Family-focused	Professional collaborates with the family and they define together what the family needs.	Family needs professional for support and guidance and use professional networks to meet needs.
Family-centered	Professionals become agents of the family and used to promote family health.	Family needs and desires drive all aspects of service delivery and resource provision.

The Dunst model is valuable in defining a stepwise progression toward development of family-centered practice. According to the literature, the transition from a professional-centered model to a family-centered one has been a gradual one. Minke & Scott (1995) conducted a qualitative study using grounded theory methods to investigate how the attitudes of professionals as experts versus professionals as collaborators affected family-centered practice. Nine families, four administrators, and ten direct

service providers participated and videotapes of IFSP meeting and interviews were used for data. They used a multiple case study approach to analyze the data and two themes emerged from the analysis of this data. The first theme was that parent-staff bonding was essential if the process of early intervention was to work. The second theme was that as relationships were established, staff members noted easier joint problem solving and parent willingness to try new behaviors. At other times, it was difficult for staff to develop close relationships and collaborate with all parents; some staff felt parents didn't always act in the best interests of the child, and it was hard to give up control to these parents. According to these comments, it appeared that these professionals verbalized willingness to engage in family-centered practice, but also articulated awareness that practicing this was not always as easy as the ideal. In response to the results of this study, the authors presented a relationship model. This model supported family-professional collaboration and encouraged staff to give the control back to parents and to empower them to make choices for their child to prepare them for lifelong advocacy for the child.

Efficacy research of family-centered early intervention practice has seen a gradual paradigm shift as well. Some of the studies that have examined this shift are summarized in Table 2. It is important to also poll the consumers of family-centered care to assess what families find as effective in intervention or what they feel is not. A number of studies have looked specifically at parent satisfaction with the family-centered model in early intervention services. These are presented in Table 3.

Table 2. Summary of Key Elements of Studies Examining the Transition to Family-Centered Practice

Study	Participants /Design	Elements	Findings
McBride, Brotherson, Joanning, Whiddon & Demmitt, 1993	Qualitative method: Semi-structured interviews of 15 families and 14 professionals	<ul style="list-style-type: none"> Investigated the meaning of family-centered intervention and the extent to which it was being implemented 	<p>Professionals:</p> <ul style="list-style-type: none"> Change in focus from child to family understood, but actual practice still variable Lacked skills to provide family-centered services. <p>Families:</p> <ul style="list-style-type: none"> Liked that therapists expressed concerns about family issues
Mahoney & Bella, 1998	47 families who attended 1 of 36 programs Using pre- and post-intervention measures, compared tests of developmental functioning to parent-child interaction to assess efficacy of the family-centered model in early intervention	<p>Developmental tests:</p> <ul style="list-style-type: none"> Bayley Scales of Infant Development Receptive and Expressive Emergent Language Scale 	<ul style="list-style-type: none"> Minimal relationship between intervention effectiveness, such as developmental gains, and family-centered services. <p>Parent-child interaction:</p> <ul style="list-style-type: none"> Maternal-child interaction styles Family Functioning Questionnaire Maternal Stress Survey <p>Family-Focused Intervention Scale (completed at midpoint)</p> <ul style="list-style-type: none"> Attributed lack of effectiveness to variability in which these programs emphasized family-centered practice <ul style="list-style-type: none"> 40% home-based services 21% center based services 38% combined center and home based
Campbell & Halbert, 2002	Survey of 270 service coordinators and therapists in a large urban early intervention system following a required professional development activity.	241 participants who completed the survey were interviewed and asked for 3 wish statements about early intervention.	<p>Service providers felt that their family-centered practice was improving because of</p> <ul style="list-style-type: none"> Communication and consultation among professionals Professional training to align with family-centered tenets <p>Anti-family-centered wishes</p> <ul style="list-style-type: none"> Better family compliance Changing service provision back to a medical and/or center based model

Table 2. Summary of Key Elements of Studies Examining the Transition to Family-Centered Practice (continued)

Study	Participants /Design	Elements	Findings
Shannon, 2004	22 family participants and 19 therapists in an early intervention system in Virginia	Participants completed survey asking what they felt were the barriers to family centered service.	<p><i>Therapists</i></p> <ul style="list-style-type: none"> • How families experience early intervention often a result of family characteristics – more motivated or tenacious – perceive early intervention services better <p><i>Parents</i></p> <ul style="list-style-type: none"> • Asked that during therapy sessions, therapists address their basic needs first, give information second, and teach therapeutic intervention third
Leiter, 2004	31 families and 19 early intervention professionals in Massachusetts	Researcher interviewed participants and observed therapy sessions	<p><i>Parents</i></p> <ul style="list-style-type: none"> • Viewed early intervention therapists as givers of emotional support and friendship • Described staff member as member of family • Comfort level allowed staff member to then serve as a conduit of clinical knowledge • Expressed concern with parent as therapist model because did not feel as competent in doing therapy as therapist does <p><i>Therapists</i></p> <ul style="list-style-type: none"> • Using a problem solving approach to give moms therapeutic skills to apply to their daily lives • Showing ways to incorporate strategies into day • Made small adjustments to activities mom and child did together anyway • Saw parent compliance with therapy as: <ul style="list-style-type: none"> ○ parent presence and active participation ○ demonstration of follow through with home work

Table 3. Summary of Evidence of Parent Satisfaction with Family-Centered Early Intervention

Study	Participants/Design	Elements	Findings
McWilliam, Lang, Vandiviere, Angell, Collins & Underdown, 1995	<ul style="list-style-type: none"> Survey of 539 parents with in-depth semi-structured interviews of 6 Parents chosen to be interviewed based on both their representativeness of the sample, and uniqueness (eg. very satisfied vs. very unsatisfied, ease in getting services vs. extreme difficulty in getting services, etc) 	Assessed parent satisfaction with early intervention	<ul style="list-style-type: none"> Families generally extremely pleased with quality of early intervention services Source of satisfaction was personal support provided by individual professionals Families felt a shortage of therapy services and difficulty in receiving the specific services they needed Need for more inclusion opportunities with typical children
Mahoney & Filer, 1996	357 mothers from 63 programs from 5 southeastern states	Completed questionnaire on early intervention programs and their responsiveness to family concerns	<p>Early intervention programs better at:</p> <ul style="list-style-type: none"> child and family instruction in development and functional activities and providing resources on child-based community service systems <p>Early intervention programs not as good at:</p> <ul style="list-style-type: none"> Providing resources for family concerns, such as housing, WIC and/or public assistance Home based services were rated better than center-based services <p>Families reported that</p> <ul style="list-style-type: none"> Need for services significantly higher than current level. Types of services received dependent on locality
Iverson, Shimmel, Ciacera, & Prabhakar, 2003	Survey of 11 parents and 18 providers in 3 different early intervention programs in metropolitan areas in Massachusetts	Surveyed perceived effectiveness of family-centered services	<ul style="list-style-type: none"> 99% of providers felt they were effective 88% of parents satisfied with early intervention program <ul style="list-style-type: none"> Need for development of parent networks Wanted to learn to value time spent with children Need for strategies in disciplining and limit setting, and available community resources

In summary, the literature presented above suggests that specialists in early intervention practice continue to struggle with the shift from professional-centered practice to family-centered practice. As the later studies show, therapists are making more of an effort to align themselves with family-centered practice now than when it was first mandated. Therapists are still placing responsibility on the family when they don't comply with their suggestions, but they are also trying harder to act as allies with families when developing strategies (Campbell & Halbert, 2002; McWilliam, Lang, Vandiviere, Angell, Collins & Underdown 1995; Leiter, 2004). Parents are also commenting on the support therapists are providing, to the extent that some parents report that therapists are like a member of the family (Leiter, 2004). That is certainly progress. The next section will present studies that have examined family-focused occupational and physical therapy practice in early intervention.

Provision of Therapy Services in Family-Centered Early Intervention

In the late 1980's, Hinojosa (1990) explored parent perceptions of occupational and physical therapy and its influence on family life. He interviewed eight mothers with a child with cerebral palsy who received OT and/or PT services to gather information on each mother's experience with home programs. One theme identified by the mothers was that home programs prescribed by the therapists didn't fit into their daily routines; therefore, the mothers would often find their own ways to incorporate treatment techniques into routines. These mothers learned to be creative and find ways to adapt play activities. They also stated that they were more likely to apply a home program if they were involved in the planning process.

A study by Edwards, Millard, Praskac and Wisniewski (2003) presented the concept of the occupational therapist as a source of support to families. Six families and four occupational therapists were interviewed to identify factors that encouraged or inhibited family-centered practice in the occupational therapy intervention process. In this study, family individuality was identified as the core concept, as families are all unique and providing the most effective family-centered occupational therapy practice involves taking this into consideration. These families all identified the relationship they developed with their occupational therapist as a significant source of support. Caregivers reportedly found that having the same occupational therapist throughout the early intervention process facilitated development of a “trusting, empathetic and genuine relationship” (Edwards et al., 2003, p. 246). Some felt that being with their occupational therapist was “like being with a friend,” and described their occupational therapist as an “outlet or sounding board” (p. 247).

Brown, Humphry, and Taylor (1997) interviewed 302 occupational therapists about the most important outcome of their interactions with client families. They developed a seven-level hierarchy of family-therapist interaction for occupational therapists who worked primarily with adults, but this model also has applications to an early intervention context. The seven family roles they identified were no family involvement, family as informant, family as therapist’s assistant, family as co-client, family as consultant, family as team collaborator, family as director of services. This last role seems to be the ideal that supporters of the family-centered model are seeking. This model is presented in Table 4.

Table 4. Seven-level Hierarchy of Family-Therapist Interaction (Brown, Humphry and Taylor, 1997)

Level of interaction	Description
No family involvement	<ul style="list-style-type: none"> ▪ most acceptably used in a biomedical model ▪ all interaction is with the client, and the family is seen as a distraction or as interfering with therapy
Family as informant	<ul style="list-style-type: none"> ▪ family is used to gather client history information
Family as therapist's assistant	<ul style="list-style-type: none"> ▪ therapist is the expert ▪ family instructed in methods to ensure continuity of therapy.
Family as co-client	<ul style="list-style-type: none"> ▪ therapist serves to minimize the drain of the person with a disability on the family ▪ adapts intervention in consideration of family needs
Family as consultant	<ul style="list-style-type: none"> ▪ family input into goals and intervention is solicited ▪ family insight is used to develop the treatment plan
Family as team collaborator	<ul style="list-style-type: none"> ▪ family process is used to help increase the independence of and integrate the client into the home and community ▪ therapist becomes the helper in this process
Family as director of service	<ul style="list-style-type: none"> ▪ family works to help its members develop ▪ therapeutic intervention may be as much focused on family functioning as it is on the client

Schultz-Krohn and Cara (2000) used Brown, Humphrey and Taylor's (1997) seven level hierarchy to discuss the challenges of shifting to a family-centered approach. The authors presented a case study applying concepts from infant mental health that illustrated a family-centered approach. With this approach, the mother in the study was empowered when she was given the role of director of service for her child. This mother-child relationship was strengthened by helping this mother to cultivate the skills she needed to be a manager and advocate for her child. By placing this mother in the role of director of service, she was empowered to exert her own authority over her child.

In another case study, Weatherston, Ribaud, and Glovak (2002) combined an Infant Mental Health Specialist with an occupational therapist to foster a family-centered

approach. The Infant Mental Health Specialist addressed the needs of the family unit by providing emotional support, developmental guidance, relationship assessment and support, and advocacy. An occupational therapist was then consulted to concentrate on the child's sensory needs which were interfering with the parent-child relationship. The occupational therapist addressed these needs by integrating sensory strategies for the child into the family's daily life. By incorporating sensory activities within the family's daily routines and occupations, these parents were validated and empowered to direct outcomes for their child.

A study done by O'Neil, Palisano, and Westcott (2001) examined the relationship of therapists' attitudes, children's motor ability, and parenting stress to mothers' perceptions of physical therapists' family-centered behaviors during early intervention. Twenty-five physical therapists and 75 mother-child dyads (3 mother-child dyads that each therapist worked with) were given the *Measures of Processes of Care-56* tool (King, Rosenbaum & King, 1995), developed by the authors, to evaluate family-centered behaviors of health care providers. Mothers also filled out the *Parenting Stress Index-Short Form* (Abidin, 1995) while their child was being assessed with the *Bayley-II Motor Scale* (Bayley, 1993). Mothers indicated that physical therapists used family-centered behaviors the majority of the time; however the higher the mothers rated their stress, the less they perceived family-centered behaviors in their therapists. Mothers also reported higher levels of stress when they had children with lower motor abilities. The physical therapists reported that they felt positive about the family-centered initiatives, but felt that services were not always individualized to the family and child needs. Three main

administrative issues that were barriers to family-centered care were identified by the therapists: IFSP meetings not being reimbursable, increased paperwork demands, and difficulty maintaining productivity levels in home-based services.

To determine if therapist perceptions were making a difference in parent-child relationships in early intervention, Mayer, White, Ward and Barnaby (2002) interviewed nine occupational therapists working in early intervention. Eight themes emerged from the therapists' experiences and reflections of their practice. All of the participants believed the parent-child relationship was of utmost importance in the child's life and this relationship was critical for the child's development. The participants articulated that they valued the parent's perspective and that parents should act as guides during the intervention. These occupational therapists also reported that they tried to work through the family, instead of trying to fix the child. The participants commented that one part of their work with families was to interpret information from other specialists and in particular how this information would affect the child's functioning within the family unit. Therapists observed that they often help parents to read their child's cues, so the parents were able to respond more appropriately with their child. Therapists demonstrated to parents positive things about their child. The therapists found they often watched parent-child interactions and looked for ways to improve these interactions within daily family routines and activities. Lastly, a common theme for all of the participants was how their focus had changed over time with experience with families, and in particular, when they had their own children. In contrast to past studies, the therapists in this study showed a very positive interpretation of their practice of a family-centered model.

In a study by Washington & Schwartz (1996), two mothers and therapists in early intervention were interviewed. In their study, two mother-therapist dyads were assessed to determine the effects of occupational or physical therapy on caregiving competency. In addition to three interviews with the mothers and one interview with each therapist, a therapy session was also observed and videotaped. These mothers felt that adaptive equipment and exercise equipment were important, but that the mother-therapist relationship and effective communication were more important in fostering perceived confidence and competence in family members. The therapists also described the importance of the mother-therapist relationship and at collaborating for goal setting and problem solving. Both mothers felt that they had an increased perception of competency in performing caregiving tasks with their children following therapy. They viewed their therapists as: “a friend, an advocate, a mentor, a troubleshooter, a source of information, and a primary source of support” (p. 44). This relationship helped foster their feelings of competency in all areas of meeting their child’s daily needs. This study supports earlier studies in the literature review about parent preferences for a supportive relationship with their therapist.

Parush and Hahn-Markowitz (1997) researched how an early intervention program affected feelings of parent competency. This random control experimental design study explored the effects of an early prevention program on increasing mothers’ sensitivity to their children’s needs and their awareness of the importance of their role in their child’s early development. This study was conducted in Jerusalem, Israel where a curriculum was offered at an existing program for mothers who attended the Mother and

Child Health Care Centers (MCHC). One hundred and nine mothers from six different MCHC centers were assigned to either an experimental or control group. The prevention program emphasized the value of appropriate sensory experiences in the first months of life and attempted to enhance the mothers' skills as mediator of her child's environment. Intervention included instruction and modeling techniques with the mother, infant, and therapist. These were presented every eight weeks during the child's first year. Mothers were asked to fill out the Knowledge, Attitude, and Practices questionnaire (KAP) 18 months after the completion of the prevention program. Results showed that the KAP scores of the intervention group were significantly higher than the scores of the control group. Since this was a random control experimental design study, these results are significant. The authors felt that the results suggested that the prevention program helped mothers acquire greater knowledge and more appropriate attitudes and practices about child development. Case-Smith (1997) discussed the significance of this study in documenting the importance of positive mothering, and in providing guidance about child rearing that enhances a mother's ability to function comfortably and competently in the parental role.

These last two studies about therapist support leading to parent competency leave a positive impression of what family-centered practice accomplish, at least in terms of the parent-child relationship. Another essential component to family-centered practice involves embedding these positive relationships into daily family routines and occupations. Therefore, in the following sections, a discussion of routines and family occupations of typical families and of those with children with disabilities will be

presented. It is the aim of occupational therapy to support positive participation in the daily occupations and routines that encompass family life. In the following sections, a discussion of the OT Practice Framework (AOTA, 2002) will be used to tie in a theoretical base to engagement in daily occupations within the family unit and later to look at how occupational therapy address family routines and occupations therapeutically.

Routines and Family Occupations

The Occupational Therapy Practice Framework

The Occupational Therapy Practice Framework (AOTA, 2002) provides a format to discuss family routines and occupations. This framework describes the work of occupational therapists as helping clients participate in their occupations and activities while also supporting the client's participation in his or her context, such as in his or her home, school, and community life situations (AOTA, 2002). The client in early intervention may be the child, the family member, or another professional, such as a caregiver. There are seven areas of occupation to consider: activities of daily living, instrumental activities of daily living, education, work, play, leisure, and social participation. When working with infants and young children, these areas of occupation might be bathing, dressing, self-feeding, playing with family members and friends, going to day care or a playgroup, and playing at the playground. To address these areas of occupation, knowledge of what specific performance skills are needed (i.e. being able to move body parts efficiently, being able to take in and process sensory and motor information, communicating needs, and interacting with others in a variety of settings)

and what performance patterns are used (i.e., such as habits, routines, and roles) is essential. Successful execution of an activity happens when the child, the environment, and the demands of the activity entwine and interact successfully. Performance patterns, such as habits and routines and roles within the family, develop over time. A child's performance skills and performance patterns are also affected by his family context or home environment (which includes cultural, physical, social, personal, spiritual and temporal aspects), activity demands and client factors (i.e.. specific body structures and functions). The demands of an activity and client factors, such as disease and disability, in turn affect the child's skills and the success of his performance.

Family-centered early intervention practice focuses on the tenet that the family provides the context in which the child most optimally develops. A child's family provides his or her first context, in that they provide the cultural, physical, social, spiritual and temporal guidelines that influence the child's performance in every day routines and occupations. In the everyday life of a family, parents use many opportunities or teachable moments to embed their cultural, spiritual, and time constraints into everyday activities and occupations. For example, sitting down to eat must be completed within a specific time frame, a prayer may be said, and culture-specific foods will be prepared. Humphry (2002) presented a dynamic systems perspective of how a child's development of occupation is centered within the context of his family. She discussed how an infant has an innate self-organizing process that helps him to integrate his immature capacities and engage in occupations. Caregiving helps to shape these emerging behaviors, so that performance becomes culturally compatible. Finally, self-

organization to maintain occupational engagement enables the child to accommodate to maturing abilities and environmental demands. A child comes with certain innate abilities and they are driven to learn and accomplish skills needed for independence. The family provides the contextual rules in how an occupation, such as self feeding will be taught. Culture-specific foods are offered, parents encourage independence when they feel it is the most culturally-appropriate time, the child follows these rules when he or she feels most ready to accomplish them. In this way, a constant interplay between the child's inner and outer context, activity demands and client factors, enable the child to use performance skills and performance patterns that enable him to be successful in his or her performance of occupations. Therefore, according to this model, the family context is a key component to the development of successful performance patterns within the family unit. To expand on this discussion of family context, studies of occupations and routines in families with typically developing children will be presented in the following section.

Families with Typically Developing Children

The successful unfolding of the family's daily occupations is influenced significantly by habits, routines, roles, and performance patterns. Studying routines and occupations within families with typically developing children gives us a better understanding of how occupations are embedded in family life. Primeau (1998 & 2000) investigated aspects of activities and occupations within families with typical children. In her study of orchestration of work and play within families (Primeau, 1998), she interviewed 10 families with preschool aged children. She used participant observations and intensive interviews using a grounded theory approach to study the nature of parents'

play with their children and how this play was orchestrated within their daily occupations. She found that parents tended to use two strategies to incorporate work and play into their family routines. When using strategies of *segregation*, families interspersed play with household work. In this approach, work and play occurred sequentially throughout the day. When using strategies of *inclusion*, play was embedded within household work or scaffolded within it. Occupational scaffolding, or the process of one occupation occurring within or as part of another occupation or in this case, child (and parent) play occurring during parent's occupation of housework, was a result of this "inclusion." Parents were observed grading the activity demands of certain tasks within their performance patterns so that the child feels competent in his participation in the occupational task.

In later research, Primeau (2000) studied how household work, routines, and child care occupations were divided in families with traditional and non traditional roles. She focused on a qualitative, multiple methods approach that incorporated participant observations, intensive interviews and a questionnaire. She studied 10 families that had two parents and a first-born child of preschool age to determine how these role differences affected participation in family routines and occupations. A family with a husband and wife participating in "traditional" roles demonstrates a clear division between the husband participating in paid work outside of the home and the wife engaging in child care and household tasks in the home. Each participant has his or her defined role with little crossover of tasks between roles. A family with husband and wife participating in "non-traditional" roles is able to share work, child care, and household

tasks equitably. Shared routines and synchronized child care were two themes that emerged from the families with nontraditional role divisions. Parents with shared routines had overlapping or identical child care routines and occupations. Synchronized child care was a way of providing seamless and uninterrupted care through simultaneous or reciprocal actions from each parent. Two themes that emerged from the families with traditional family roles were separate routines and maternal responsibility and paternal assistance. Parents with separate routines used a different routine for the same activity, such as bath time. Maternal responsibility and paternal assistance referred to the paternal perception in these relationships that when the father performed childcare, he was helping out the mother, who was the one who really had primary responsibility for the children. In this study, the social context strongly affected the performance patterns of these families in their household work, routines, and child care occupations.

Primeau (1998) discussed how parents incorporated their child's play occupations within their own performance patterns to support their child's development. Primeau (2000) also discussed how the social context of the family affected family performance patterns. The physical context is another way that parents influence their child's performance. Pierce (2000) used a grounded theory approach to study the contextual features of how 18 mothers managed the spaces and objects of their homes to support their infants and toddlers at play. Each mother and infant dyad was visited monthly from one month until 18 months of age. Mothers were interviewed and infants were videotaped at play at each visit. Data collection focused on changes in the infant's and toddler's object play interests, use of home space, play sequencing, developmental play changes,

and maternal supports to play. Results showed that much of these mothers thinking and practices of managing infant play revolved around the play objects in the physical environment. Another theme was that supporting infant play in the home was synonymous with supporting infant development. The mother's work of providing manipulation and exploration of objects was crucial to infant development, and critical thought was put into what toys were appropriate and challenging for the child's developmental age. These mothers capitalized on the physical context to affect activity demands. As each child in the study aged and became more mobile, each mother found ways to change the physical context of the home space and its management routines to accommodate the infant's increasing independence in exploring and negotiating the home space. Mothers went to great lengths to adapt the child's environment into a safer place with various child safety devices. Positioning devices were also used to enhance developmental play possibilities, as well as to safely contain the infant so that the mothers engage in household work activities. All of these contextual features of the child's environment played into the challenge of activity demands and were positioned and postured to improve performance skills and ultimately enhance development of occupations. Providing safe and challenging play opportunities became a focus of these mothers' daily roles, habits and routines.

Parents use the physical context to enhance their child's skills. What the child needs developmentally from his physical environment changes as he grows and matures. Francis-Connolly (2000) proposed two motherhood stages, preschool-aged and young adult, to understand the tasks and activities involved in the caring and nurturing of

children. She utilized in-depth semi-structured interviews to examine these stages with 40 mothers, 20 with preschool aged children and 20 with young adult children. Results identified two themes for the mothers of preschool aged children: motherhood immersion and enfolded activity. Motherhood immersion was a description of the intense, endless and oft-times overwhelming demands of young children. Enfolded activity refers to how these mothers often enmeshed childcare activities into household tasks. Teaching, playing, and nurturing activities were all enfolded into the routine of mundane daily tasks. The theme that emerged for the mothers of young adult-aged children was that of invested participant. These mothers remained invested in their children's lives and continued to provide instrumental and emotional support for their children, as well as a safe home base, although their children no longer lived at home and led largely independent lives. These mothers were available to provide this support as needed. The theme that was common to both stages was that caring, nurturing and teaching activities continued throughout both of the mothering stages and these were the roles and routines that these mothers embraced. For these mothers, activity demands and performance patterns of their specific mothering stage formed each mother's roles, habits and routines for herself at that stage to support the context and performance skills of her child.

Another study that presented findings of differing family routines and rituals at two different parenting stages, infancy and preschool age was done by Fiese, Hooker, Kotary and Schwagler (1993). These authors examined the organization of the family system by studying family rituals at two points in early parenthood. Information from the *Family Ritual Questionnaire* and couple interviews was gathered from 54 couples with a

child of 12 months or less and 61 couples with a child between 24 and 66 months. Perceptions of marital satisfaction were gathered with the *Dyadic Adjustment Scale*. The results showed that the preschool family group reported practice of more family rituals and ascribed more meaning to these rituals than the infant family group. Marital satisfaction was also higher for the preschool family group and the authors attributed this to the protective function of meaningful family rituals. The conclusions that the authors found in this study suggest that performance patterns, in the form of family rituals, provide the backbone for effective occupational performance.

Families with Children with Disabilities

Strategies for Orchestrating Occupations

This section will present those studies that have focused on how families adapt their routines and occupations to their child with a disability. In Larson's (2000) qualitative study on how mothers orchestrate their occupations to meet their child's and family's needs, she used multiple in-depth interviews, scales of well-being, and participant observation with six mothers of Mexican-origin. She wanted to understand the relationship between mothers' subjective well-being and orchestration of daily occupations. Her results revealed that these mothers closely linked their successes in mothering a child with a disability to their feelings of subjective well-being. These mothers identified the following eight processes of composing maternally-driven and child sensitive occupations: planning, organizing, balancing, anticipating, interpreting, forecasting, perspective shifting, and meaning making. These mothers often talked about how additional planning and organizing were needed to complete all of their daily plans.

Balancing, a process of including the interests, preferences and desires of all of the family members was an integral part of this orchestration process. Anticipating the rough spots in daily routines assisted in making these routines successful for all family members.

These mothers became experts at interpreting their child's desires, needs and preferences and these interpretations were used in the design of the child's daily occupations.

Mothers also tried to forecast possible futures for their child to guide and give direction to how they adjusted the particular activity demands of an occupation to challenge the child. Perspective shifting and meaning making were used by the mothers to manage the frustrations that occurred with the unsuccessful implementation of daily occupations.

Perspective shifting used a mental process of revising previous events, such as coming to terms with the child's diagnosis, and finding ways to seek family fulfillment despite the child's disability. The process of meaning making, often occurring along with perspective shifting, involved finding alternative spiritual, meaningful, and optimistic explanations for life circumstances and occupational patterns. In this study, the mothers used different processes to orchestrate their daily activities within different contexts. They used the interaction between their own motor, process and communication/interaction skills and the activity demands to incorporate a contextual perspective for successful performance patterns. Successful performance in daily habits and routines then ultimately led to successful performance in their occupations and the occupations of their child and family.

Segal (2000) also discussed strategies mothers used in adapting their routines and occupations to meet the needs of their school-aged child with ADHD. She conducted in-depth interviews with 17 families with a child with ADHD and asked them to describe

their daily schedule, routines, and occupations. These families discussed three adaptive strategies they used: enfolding occupations, temporal unfolding of occupations, and unfolding occupations by “inclusion.” Similar to Primeau’s (1998) study discussed above, enfolding play with household work was a strategy used by parents of some typically developing children to be able to spend more time with their children. For these mothers, enfolding was often difficult and was most commonly used when no other options were perceived, particularly with morning routines. Temporal unfolding occurred when mothers reconstructed their own occupations so that they focus on the child’s occupational performance. This might involve arising earlier and completing parental occupations before addressing the child’s needs. Unfolding occupations by “inclusion” involved “delegating occupations or chunks of activity to another person to strategically eliminate occupations in their routines, and therefore, enhance their ability to meet the child’s needs” (p. 303). This delegating of previously unfolded tasks helps relieve the mother’s stress and burden and better enables the child’s occupational performance. These mothers often had difficulty meeting the activity demands of various habits and routines, and discovered strategies to unfold activities or found ways to unfold them by “inclusion” to improve the child’s effective occupational performance.

Changes and Compromises Made for the Child with a Disability: Realigning One’s Life Path

A strategy parents used to adapt to a child with a disability was to realign their life path to the life path of the child. Larson (1996) completed a narrative analysis of the dimensions of adaptation in her in-depth study of one mother-child life history. She used

in-depth interviews, participant observation, and document reviews to look at one mother's adjustment to her child with a disability. This mother born in Mexico gave up a successful professional life as a doctor in Mexico and her family's support to find the best care for her child with severe disabilities in the United States. Larson found that this mother saw her adaptation to her child with a disability as realigning her life path to the desired life course of being with her child. She was not able to evaluate her personal occupational success in the present, but instead saw it as part of a whole. Each decision this mother made for her child's and her own life course was within the temporal context of that decision and was part of a temporal stream of her and her child's life course. This mother's life choices were driven by her maternal values to be a good mother to her child with a disability, and her achievement of personal goals were diminished, except in relation to her maternal and spiritual roles. This study was significant in that it shows how contextual factors (i.e., cultural, social, personal, spiritual, and temporal) have a strong influence on the performance patterns and ultimately the occupational performance of this mother. The child's disability was an occurrence that caused a change in the trajectory of this mother's life to align her life with that of her child's life.

Role changes are often required for a parent with a child with a disability to align with the child's life path. A study by Crowe, VanLeit, Berghmans, and Mann (1997) examined perceived past present and future occupational roles of mothers of young children. One hundred and thirty five mothers of children ages six months to five years of age completed the *Role Checklist* (Oakley, Kielhofner, Barris & Reichler, 1986). The 45 participants were divided into categories by their child's diagnosis: multiple disabilities,

Down syndrome, and typically developing. The mothers of children who were typically developing reported that they engaged in significantly more present roles than the mothers in the other two groups. All three groups lost a significant number of roles from the past since their child was born, and there were no significant differences in the groups between the values they placed on their roles. This study supported the view the added activity demands of caring for a child with a disability has the potential to decrease the number of roles a mother engages in and leads to reorganization of performance patterns to meet the occupational needs of the child.

Making changes and compromises for the child with a disability impacts a parent's satisfaction with time use. Vanleit & Crowe (2002) investigated the outcomes of an occupational therapy program on the mothers of the children in the program in terms of their perceptions of time use and occupational performance. Thirty-eight mothers of children, ages three to 13, with disabilities were randomly assigned to participate in either the treatment or control group. The Canadian Occupational Performance Measure (COPM) was used to assess baseline and post-treatment levels of participants' self-perception of occupational performance and satisfaction over time. The intervention targeted facilitating increased perceptions of satisfaction with time use and occupational performance through one individual and six group therapy sessions. Although no significant differences were found between the two groups, the authors felt that just completing the questionnaires may have helped all of the participants, both in the control and experimental groups, to think about time use, occupations, and come up with ways to

make positive changes. By addressing specific contextual factors through the questionnaire, these authors felt that the performance patterns of the subjects improved.

Case-Smith (2004) employed an ethnographic approach to study how parents managed to meet the caregiving demands of their children with chronic medical conditions, while managing to maintain social lives, and continuing to form a self-identity. Eight parents participated in the study and graduate students performed the interviews and spent 60 hours over a six month period with each family observing them engaged in typical activities and routines. The children in the study were between four and six years of age. Three themes emerged from the data related to managing caregiving responsibilities. Parents discussed the challenge of always being there for their child and the difficulty in coordinating medical, educational, and recreational tasks for their child. Parents identified decisions and compromises they had to make for the child, including changes in career plans so that one parent stayed home and cared for the child with special needs. The themes related to families' social lives revolving around trying to find a child care provider, and anticipating the unanticipated (or unexpected), and using elaborate planning to leave the house. The themes that emerged from the families in regards to self-identity included parent expressions of how their child with a disability had helped them to learn to appreciate and celebrate life and be more sensitive and tolerant of individual differences. These parents learned to become strong advocates for their children, and other children with similar needs. This article stressed the activity demands of managing care of a child with disabilities and how these factors interfere with trying to maintain social participation.

The Importance of Engaging in Daily Routines and Occupations

Segal (2004) explored how family daily routines and rituals are important for the family's functioning and sense of identity, especially in the family that has a child with a disability. Using data drawn from a larger body of research on daily schedules, routines, and occupations in families of children with special needs, Segal analyzed the morning routines of 40 families with children with special needs in the United States and in Canada. Forty of the 49 participants were mothers. Families were interviewed between one to four times to gather optimal data. Segal used a description of family rituals from an article by Fiese, Tomach, Douglas, Josephs, Potlrock and Baker (2002) who describe them as: "a form of symbolic communication that conveys the family identity (who we are), imparts to the participating individuals a sense of belonging to the family, and provides continuity of meaning across generations" (p. 500). She differentiated these from routines, which she described as patterned behaviors that have instrumental goals. "Routines give life order whereas rituals give it meaning" (p. 500). Segal felt that the way that the participants chose to discuss some of their morning routines transformed them into rituals, as they were rich with symbolic and affective meanings. The descriptions the participants used to describe some of their morning routines went beyond rote descriptions of the activities themselves, but imbued a sense of each person's role/identity in the routine and belongingness to the family. When the families described a routine, instead of a ritual, it was described as behaviors patterned around completing an occupational goal. No symbolic or affective meanings were attached to it. One family in the study talked about how a lack of routine for them felt like a lack of order for their

family. This study suggests in many ways how performance patterns, such as routines and rituals truly support and provide a backbone to successful engagement in occupations.

In an earlier study, Segal (1999) examined occupations in 25 families with children with special needs. She used qualitative research interviews to ask open-ended questions of parents of children with special needs to describe their life experiences. These families described the three purposes of their shared family occupations as: being together, sharing, and providing learning occupations for the children. “Being together” was about funtime. They were things that the children liked to do and family interactions were relaxed and undemanding. “Sharing time” usually occurred during family meals and involved clear behavioral expectations of the children. They were supposed to sit for the entire occupation, talk, and share their day. “Providing learning” occupations for the children involved conveying and sharing with the children the family’s religious views, its ethnic and family background, or its hobbies and interests. In this study, families of children with special needs used shared family occupations to embed performance skills and patterns within the family’s own context.

The Challenges of Engaging in Family Routines and Occupations

Cronin (2004) and Degrace (2004) both conducted qualitative studies about parenting children with disabilities and the difficulties with engaging in daily routines. Cronin worked with mothers of children with attention deficit hyperactivity disorder (ADHD) and compared their parenting experiences to mothers of children with cystic fibrosis (CF) while Degrace (2004) focused her study on mothers of children with autism.

Cronin interviewed 22 mothers of children with ADHD and 22 mothers of children with CF. Children in the study ranged in age from five to 18 years. Open-ended questions were used to examine family demands, resources, time use, routines, concerns and support. The mothers of the children with CF reported persistent emotional sorrow over the diagnosis, but felt they were able to try to normalize the child's daily routines through family and outside supports. The mothers of the children with ADHD verbalized that they had no such thing as a normal day, and talked frequently about lack of family support and high child related demands, which resulted in these mothers feeling less confidence in their mothering skills. The mothers reported that they were often exhausted in their role of mother because their child did not easily conform to social standards and the mothers felt that this reflected on them. With phenomenological qualitative methods, DeGrace (2004) examined five families' experiences with negotiating family daily life and the meanings they gave to these experiences when they had a child with severe autism. The children with autism in these families were between nine and ten years. These families reported that their whole family life revolved around the child with autism and that they often felt robbed as a family; they had only fleeting moments of feeling like a family and much of their time was spent trying to either occupy or pacify their child to keep him in a manageable state. In both studies, the families articulated a lack of normal family routines and/ or a lack of feeling like a family or like a competent parent. In both studies, these parents of children with ADHD and autism identified high activity demands placed upon them, a lack of belief in success in these demands, and a lack of belief in competency in the occupations of parenting or in creating a successful family unit.

Exploring the literature on family routines and occupations in families with children developing typically or with children with disabilities is important in any discussion of family-centered early intervention practice because routines and occupations are the essential components to holistically and successfully treat a child in this area of practice. The next area in this literature review will explore how sensory function in infants and children affects their ability to participate in daily routines and occupations, such as sleeping, eating, playing and self-regulation. The research on intervention techniques specifically targeting sensory processing and sensory strategies used in early intervention practice will also be presented, along with how these might fit into a family-centered treatment model.

Examination of Sensory Processing and Sensory Diets in Family-Centered Practice

Sensory Processing: Definitions

Clinicians have long hypothesized the prevalence of sensory processing disorder, but research by Ahn, Miller, Milberger and McIntosh (2004) systematically examined the estimated rates of this disorder with survey data. Parents of incoming kindergartners in one Western school district were surveyed using the *Short Sensory Profile* (McIntosh, Miller, Shyu, & Dunn, 1999a). It was found that between 5.3 % and 13.7 % of these children met the criteria for a sensory processing disorder. Given this frequency, it is imperative to continue study of sensory processing disorders as well as the means to address sensory processing issues in children.

Before embarking on a discussion of studies on sensory processing, a definition and a conceptual model of sensory processing will be presented. Bundy, Lane and

Murray (2002, p. 480) define sensory processing as “functions related to sensation occurring in the central nervous system; includes reception, modulation, integration, and organization of sensory stimuli; also includes the behavioral responses to sensory input.”

Dunn (1997) presented a conceptual model of sensory processing that directly ties how a child processes sensory information to his behavioral response to it. She referred to the ability to modulate and process sensory information as a neurological *threshold* for this type of information. “Thresholds” fall anywhere along a spectrum between high and low. Young children who have high neurological “thresholds” react less readily to sensory input, and also take a longer time to react. In young children with low sensory “thresholds,” their neurons trigger more readily and therefore they have more frequent reactions to sensory input in their environments. Behaviorally, children respond according to their sensory “threshold,” or they respond to counteract their sensory “threshold.” There is a continuum of “thresholds” and responses for this model and children with typical sensory processing can fall within this range. “Thresholds” and responses are seen as atypical if they interfere with a child’s participation in daily routines and occupations typical for his age. Table 5 summarizes Dunn’s conceptual model. Dunn’s model is important to consider because it seeks to predict functional behavior that is contingent upon neurological sensory processing “thresholds.”

While developing the above model, Dunn and her colleagues designed the Sensory Profile (1999) and have sought to use this tool to compare the results of children with typical development to children with specific diagnoses, such as Attention Deficit

Table 5. Dunn's Conceptual Model of Sensory "Threshold" (1997)

Neurological "Threshold"	Behavioral Response in Accordance with "Threshold"	Behavioral Response that Counteracts the "Threshold"
High	<i>Poor Registration:</i> <ul style="list-style-type: none"> • Appears inattentive • Clumsy • Has trouble getting going 	<i>Sensation Seeking:</i> <ul style="list-style-type: none"> • Constantly moving • Bumping into objects and other children • Unable to sit still
Low	<i>Sensitivity to Stimuli:</i> <ul style="list-style-type: none"> • Balks at transitions • Prefers strict routines 	<i>Sensation Avoiding:</i> <ul style="list-style-type: none"> • Cautiously plans movements and interactions to avoid uncomfortable sensory input

Hyperactivity Disorder (ADHD) and autism. The Sensory Profile is an important tool to consider because it identifies sensory behaviors embedded within the child's occupational performance in his natural context (e.g. home and community settings). Table 6 presents a representation of some of the studies Dunn completed to document to efficacy of the Sensory Profile in targeting sensory processing issues.

The Sensory Profile underwent changes to expand the instrument from 99 to 125 test items as seen in the increase in test items from the study in 1997 to the study in 2002. Despite these changes, the results of these studies continued to demonstrate that children with diverse diagnoses show different behavioral responses to sensory input and these responses may affect their ability to participate in occupations in their natural environments. Sensory processing is a client factor that affects a child's performance skills and patterns, and dysfunction in these areas in turn affects a child's occupational performance within his natural environments.

Dunn (2002) recently developed The Infant/Toddler Sensory Profile as an assessment specifically targeted to address children from birth to three years of age.

Table 6. Dunn's Studies Documenting Sensory Profile

Study	Child whom Sensory Profile Completed	Findings
Kientz and Dunn, 1997	<ul style="list-style-type: none"> • 32 children with autism (ages 3-10) • 64 children without (ages 3 -13) 	<ul style="list-style-type: none"> • 84 of 99 items on Sensory Profile • Differentiated sensory processing of children with autism from typical children
Ermer and Dunn, 1998	<ul style="list-style-type: none"> • 38 children with autism or PDD • 61 children with ADHD • 1,075 children without disabilities 	<ul style="list-style-type: none"> • Discriminated between children with disabilities (ones included in analysis) and those without • Discriminated between two groups of children with PDD/autism and ADHD by responses on Sensory Profile
Dunn, Myles, and Orr, 2002	<ul style="list-style-type: none"> • 42 children with Asperger Syndrome • 42 children without disabilities (8 to 14 years) 	<ul style="list-style-type: none"> • On 22 of 23 items related to auditory processing, children with Asperger Syndrome showed significantly different results than children without disabilities.
Dunn and Bennett, 2002	<ul style="list-style-type: none"> • 70 children with ADHD • 70 children without (ages 3 to 15) 	<ul style="list-style-type: none"> • On 118 of the 125 items on the Sensory Profile, children with ADHD had significantly different responses to sensory events

Development of the Infant/Toddler Sensory Profile included soliciting 401 parents to complete the 81 item questionnaire (Dunn & Daniels, 2002) regarding their infant or child who was typically developing. Parent groups were divided into six month intervals determined by their child's age. A frequency distribution was compiled of parents' responses to each item within the six month age groups. These distributions revealed that parents of infants (birth to six months) only answered some of the items; those parents with children above six months were able to answer most of the items.

Forty-eight of 81 items best characterized sensory processing for children seven to 36 months, and 36 of the 81 items were the best fit for infants six months and younger.

Because it was specifically developed for children age birth to three years, the

Infant/Toddler Sensory Profile is a helpful tool for early intervention practitioners to use to assess a young child's sensory processing problems.

Self-Regulatory Problems

Sensory processing difficulties present differing dilemmas for infants, children and their families as they grow and mature. In infancy, sensory processing disorders are often related to regulatory problems, such as sleep difficulties, poor self-calming, very low or high activity level, and atypical muscle tone resulting in slow attainment of motor milestones, and under- or over- responsiveness to sensory stimulation (Wiener et al., 1996). Therefore, client factors that hamper a child's successful participation in his family routines and occupations may relate to sensory processing and self-regulation in infants and young children. DeGangi et al. (1993) performed a prospective descriptive study of the developmental outcomes of nine infants with moderate to severe regulatory disorders who did not receive intervention. At the time the study was conducted, the clinical significance of regulatory problems was not known, and treatment was not considered. Infants with regulatory disorders were defined as those who were behaviorally difficult, had disturbances of sleep, feeding, state control, self-calming and mood regulation, and demonstrated poor sensory processing. The infants were initially examined at eight to eleven months and again at four years of age and their scores were compared to the scores of 13 infants developing typically. The infant assessments used were as follows: the *Bates Infants Characteristics Questionnaire* (temperament), *Test of Sensory Functioning in Infants* (sensory processing, behavioral organization and sensorimotor integration), and the *Bayley Scales of Infant Development* (developmental

and perceptual competence). The preschool age assessments utilized were as follows: *Sensorimotor Questionnaire* (emotional maturity/behaviors, and responses to touch and movement), the *DeGangi-Berk Test of Sensory Integration* (behavioral organization and sensorimotor integration), and the *McCarthy Scales of Children's Development* (developmental and perceptual competence). At follow-up assessment, eight of the nine children with regulatory disorders displayed developmental, sensorimotor, and /or behavioral deficits at four years. Differences were found in attention and activity level, emotional maturity, motor coordination, and tactile sensitivity. The results from this study suggest that children with regulatory disorders as infants, if untreated, may not outgrow these difficulties over time. The results suggest that regulatory difficulties continue to hamper developmental skills and the ability to successfully engage in childhood occupations.

Wiener et al. (1996) conducted a study to determine the differences in sensory processing among typically developing full term infants, infants born prematurely, and full term infants with a regulatory disorder. The TSFI was administered to 329 infants, ages seven to 18 months. Two hundred and twenty-eight of the infants were considered normal, 45 had regulatory disorders, and 56 of the infants were born prematurely. The infants with regulatory disorders were given this diagnosis because they had problems with sleep and eating, signs of high irritability, and severe separation anxiety. In this study, both the infants who were born prematurely and the infants with regulatory disorders scored lower on the TSFI than the typically developing infants in all of the

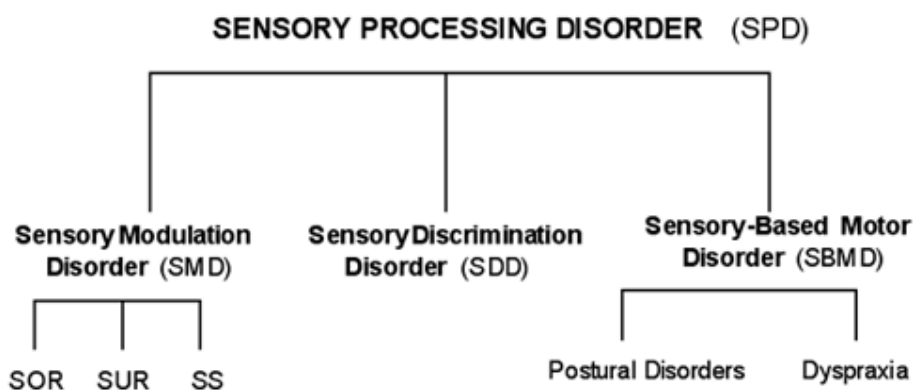
areas assessed, including tactile-deep pressure reactivity, visual-tactile integration, adaptive motor skills, movement in space, and ocular-motor control.

Both of the above studies suggest that infants with sensory regulatory issues may be at risk for poorly developed occupational patterns due to problems with sleeping, eating and transitions. Mother-infant bonding also may be affected by these sensory processing issues. DeGangi et al. (1997) explored mother-infant interactions in a study of infants with self-regulation disorders. Ninety-four infants with regulatory disorders and 154 normal infants ranging in age from 7 to 30 months participated in the study. The Infant/Toddler Symptom Checklist was used to confirm the presence of regulatory problems. Mother-infant dyads were observed and videotaped for five minutes engaging in three types of play: symbolic, tactile, and vestibular. Results demonstrated that during play with textured toys, infants with poor regulation had significant difficulty with engagement and sensorimotor exploration. They found that between 50% to 85% of the sample (depending on age group) demonstrated tactile hypersensitivities to being touched by others and to touching textured toys. The majority of these children also displayed a flat affect during the tactile play. Despite these difficulties during the tactile play, the infants with regulatory disorders were focused and engaged during the symbolic and vestibular play conditions. The mothers, on the other hand, showed flat affect during the movement play. They also tended to verbally prompt their child to play with the movement equipment, and avoided moving their child onto the equipment. This study has significance because it demonstrates some of the strategies mothers use to engage or disengage their child with regulatory issues to provide an optimal play experience. These

strategies are often used by therapists as a starting point in treatment to guide parents in what child-directed cues they are already using in their play with their child.

Measures of Sensory Processing

Miller, Cermak, Lane, Anzalone, and Koomar (2004) also developed a conceptual model to classify the different types of Sensory Processing Disorders (SPD). They identified three different dysfunctional patterns of sensory processing: sensory modulation disorder, sensory-based motor disorder and sensory discrimination disorder. This model is presented in Figure 1.



SOR = Sensory Over -Responsivity
 SUR= Sensory Under -Responsivity
 SS= Sensory Seeking / Craving

Figure 1. Current Taxonomy for the Identification of Sensory Processing Disorders (Miller, Cermak, Lane, Anzalone & Koomar, 2004)

Persons with sensory modulation disorders (SMD) demonstrate behaviors to sensory information that do not match its actual nature and intensity. They are over-responsive, under-responsive, or demonstrate sensory seeking or craving behaviors. A child who is over responsive to sensory input might interpret a light touch from another child as hitting or be distracted by the noise of a fan three rooms away. A child who is

under-responsive to sensory input may prefer sedentary activities and have difficulty getting himself moving. A child with sensory seeking behaviors might react to sensory under-responsiveness by being constantly on the go or seeking lots of hugging and physical contact from his or her peers. Persons with sensory discrimination disorder (SDD) have problems with sensing the similarities and differences between specific sensations, such as vision, hearing, touch, taste/smell, and position/movement. Children with SDD require extra time to process sensory information because they have difficulty deciphering what they are experiencing as quickly or as naturally as other children. A child with SDD might have difficulty identifying what is in his hands without looking, or trip and fall often because he has a poor sense of where his body is in space. Sensory-based motor disorder (SBMD) refers to persons who have difficulty with holding positions, moving, or planning and sequencing movement in response to sensory demands. Dyspraxia and postural disorders are subcategories of this disorder. Children with dyspraxia have difficulty with sequencing and planning gross motor, fine motor and/or oral-motor movement. Children with postural disorder have difficulty with motor movements because of low muscle tone and/ or weak postural musculature (Miller, 2006).

Miller (2003) has also looked at how sensory processing affects behavior. In her 2003 article, she commented on the lack of empirical data to support whether sensory-based occupational therapy is an effective intervention. Therefore, she and her colleagues have sought to conduct studies that present empirical reinforcement for sensory-based processing and its effects on behavior. In a study by McIntosh, Miller, Shyu and

Hagerman (1999), the authors hypothesized that children clinically identified with sensory-modulation disorders (SMD) would have atypical physiological responses to sensation, and that these responses would predict parent-reported functional behavioral responses to sensation. Nineteen children clinically identified as having SMD and 19 control children without SMD, who were matched for gender and age, participated in the study. Children in the SMD group were recruited from the OT department at the Children's Hospital in Denver, and demonstrated difficulties in behavior regulation during intake, had parental reports of significant symptoms in at least two sensory domains, and had confirmation of modulation difficulties during the parent interview. The control sample was recruited from Denver, Colorado and had no significant history of birth or other trauma, or unusual development. Each participant received the Sensory Challenge Protocol, developed by the authors, that included olfactory, auditory, visual, tactile, and vestibular input, all administered in that order. Electrodermal responses (EDR) were recorded throughout the session. EDR measures electrical conductance in the skin, which is associated with the activity of the sweat glands. The more emotionally aroused a person is, the more active his or her sweat glands are and the greater the electrical conductivity of his or her skin. Parents of each participant were asked to complete a modified version of the Sensory Profile (Dunn, 1994) that was condensed by the authors into a 51 question survey. Results confirmed that among the participants who did respond to the EDR, the children with SMD showed more electrodermal responses and responses of greater magnitude than the control children. When the number and proportion of responses were measured, the children with SMD also habituated more

slowly than the group of control children. Lastly, those children who showed abnormal patterns of electrodermal responses also showed more behaviors associated with abnormal responses to sensation, as reported by parents on the revised Sensory Profile. This study supports Dunn's idea that children with sensory processing difficulties experience sensation differently at the body function/structure level and that this difference often is seen in their performance skills and patterns as well.

Sensory Diets

Miller (2003), in a discussion of the need for empirical evidence of therapies for sensory processing impairments, stated: "current best practice intervention for children with sensory processing impairments is intervention focused on 'occupation' not treatment using specific sensory techniques in isolation" (p.2). In best practice sensory diets are embedded within a child's and a family's daily occupations. According to Wilbarger (1995), who coined the term, sensory diets are described as the "just right combination of sensory input to keep an optimal level of arousal and performance" (p.1). She further illustrated sensory diets as similar in nature to nutritional diets. Nutritionally, each person has various diet needs throughout the day or week that include large meals, but also incorporate snacks. To keep the average person at an optimal level of arousal and performance, a person needs to find and incorporate various sensory experiences throughout his day. Some of these sensory experiences might be like large meals, such as heavy work activities like exercise, which have longer lasting effects on boosting arousal and performance, and others will be like snacks, such as a fidget toy which might keep a person alert for a brief period of time. For families in early intervention, a successful

sensory diet needs to be embedded within the context of daily life; otherwise the child or family will find it burdensome and too cumbersome to implement. Coster (1998) in her discussion of occupation-centered assessment for children supported this concept. She suggests that the measurement of intervention success for a child with sensory defensiveness was not whether there had been a change in the child's sensory processing, but whether there had been a change in his or her occupational engagement in an activity, specifically to a pattern that promoted personal satisfaction and supported growth.

Sensory Diets in Family-Centered Practice

How can sensory processing and sensory diets be examined in family-centered practice while remaining embedded in an occupation-centered framework? Dunbar (1999) used an occupational performance model to present a case study of a three year old girl with sensory processing problems. The occupational performance approach focused on what the client and/or family members perceived to be the important issues causing difficulties in daily activities. This model used the person (client and performance skills), the environment (human and nonhuman contexts), and the occupation (meaningful activity) and examined how they relate to each other in supporting the child's and family's roles, and their daily routines and occupations. For Dunbar's case study, a sensory history and the *Early Intervention Developmental Profile* were completed by the child's mother. The child was evaluated with the *Degangi-Berk Test of Sensory Integration*. The child's mother reported in the sensory history specific concerns with the child's risk-taking and socially intrusive behaviors. The *Developmental Profile* showed that the child had age appropriate developmental skills. Results from

Degangi-Berk Test of Sensory Integration showed that overall functioning was found to be in the deficient range, with particular difficulty with sequencing motor actions.

Intervention included center-based sensory integration therapy once a week and home program of activities collaboratively planned by the therapist and the parents. Results of the therapy program after three months were that this child attained all of her three month therapy objectives, was able to sleep for longer periods of time, and engage quietly in tabletop activities with decreased incidence of tantrums and head banging. Significant results from the intervention for the parents were that the child's mother gained an awareness of her sensory needs and independently initiated sensory based interventions as the child's behaviors warranted. This child's occupational behaviors not only improved after receiving therapy, but her parents also learned how to modify the child's environment to optimize her occupational functioning.

Dunbar's model was certainly an occupation-based approach that used family-focused techniques, but because all of the therapy with the child was center-based, this author's method was not strictly applied to early intervention practice based in the natural environment. Since traditional sensory integrative occupational therapy is performed in a clinic setting, it is particularly challenging for occupational therapists who embrace this model to truly accept and support a family-centered early intervention model. There have been various studies that sought to look at the efficacy of sensory integration techniques with various populations and they have shown various results (Miller, 2003; Vargas & Camilli, 1999), but these studies were often based in clinical or school-based settings. Another compelling issue is that occupational therapists often prescribe sensory diets for

clients, but there have been no efficacy studies done on what specific activities should be encompassed in a sensory diet. Since there is no existing research on what a sensory diet should include, and because traditional sensory integration settings don't fit the family-centered early intervention model, the remainder of the studies presented here will focus only on characteristics of sensory diets. None of the following studies, however, will be able to encompass all of these aspects into current family-centered early intervention practice because studies of this type don't yet exist.

Efficacy Studies of Sensory Diet Techniques

Various studies have examined how specific intervention techniques, such as deep pressure or proprioceptive activities and weighted vests, were effective in controlling certain behaviors in several small sample studies. Deep pressure or proprioceptive activities include activities that provide deep input into the skin, muscles and joints and include: massage, burrowing in heavy pillows, pushing, pulling, or carrying heavy objects, or playing in a tub of raw beans or a ball pool (Koomar & Bundy, 2002). Studies about weighted vests (which have pockets with .25 pound or .5 pound weights in them) will be presented briefly because many of these treatment techniques are described by Wilbarger (1995) as strategies that are necessary for developing a sensory diet. Wilbarger stated that “activities that include deep pressure tactile, vestibular, or proprioceptive inputs are thought to have the most pervasive effect on behavior” (p.3). Koomar & Bundy (2002) also felt that deep pressure and proprioception are important therapeutic tools in sensory integration intervention.

Edelson et al. (1999) investigated the effects of deep pressure using Grandin's Hug Machine on arousal and anxiety reduction in five children with autism, aged four to 13 years, (seven children in the control group received placebo treatment). Arousal was measured behaviorally with the *Conners Parent Rating Scale* and physiologically with galvanic skin response (GSR). Children in the experimental group were trained to use the Hug Machine lever to provide deep pressure as often as they wanted to during a 20 minute session. Children in the control group lay in the Hug machine, but the lever was disengaged. Each child received 12 sessions with the Hug Machine. GSR was measured before and immediately after each session. GSR probes were attached to the index and middle fingers of the child's right hand. Parents were instructed to complete the Connor Parent Rating Scale before the first session, after the sixth session, and after the 12th session. Behavioral results showed a significant reduction in tension and a marginally significant reduction in anxiety for the children who received deep pressure when compared to those who didn't. GSR measures also decreased significantly for the experimental group.

Neu & Brown (1997) studied physiologic and behavioral organization of 14 infants born prematurely during swaddled versus unswaddled weighing in a NICU setting. Effects of the swaddled versus unswaddled weighing was examined using the Assessment of Behavioral Systems Organization scoring tool (ABSO) and by monitoring heart rate, respirations and oxygen saturation levels. The ABSO rated the behavior of each infant in terms of physiologic (autonomic) organization, motor organization, effectiveness of self-regulatory behaviors, and need for caregiver assistance. A repeated

measures crossover design was used in which the infants were exposed to both swaddled and unswaddled weighing. Infants were weighed on two consecutive nights, one night swaddled and the other night unswaddled. Infants were randomly assigned to whether they would be swaddled or unswaddled on the first night. These authors found that when swaddled, the infants in the study showed less physiological distress and more effective self-regulatory ability during weighing than the unswaddled infants.

Two studies examined the efficacy of weighted vests. Fertel-Daly et al. (2001) studied the effects of a weighted vest on attention to task and self-stimulatory behavior in 5 preschoolers (age 2 to 4 years) with pervasive developmental disorders (PDD). Participants wore the weighted vest with a .25 pound weight in each of the four pockets for 2 hours. All participants were observed wearing the weighted vest at a table during a fine motor task for 15 sessions over a 6- week period. Duration of focused attention, number of distractions, and duration of self-stimulatory behaviors were recorded on a data collection sheet. During the intervention phase, all of the participants showed a significant decrease in the number of distractions and an increase in the duration of focused attention while wearing the weighted vest. Four of the five participants demonstrated a decrease in the duration of self-stimulatory behavior, and the other child had a decrease in the intensity and number of self-abusive stimulatory behaviors. During the withdrawal from intervention, self-stimulatory behaviors and number of distractions increased and duration of focused attention decreased in the participants, but they never returned to pre-intervention levels. A study by Olsen & Moulton (2004) examined therapists' perception of the efficacy of weighted vests in therapy. The researchers

surveyed 514 pediatric occupational therapists with a 68% response rate. These therapists reported that they noted an increase in children staying on task, staying in their seats, and improved attention span following the use of a weighted vest.

A final study explored the effects of sensory integration treatment on self-stimulating and self-injurious behaviors at a residential facility for children and adults with developmental disabilities. The authors (Smith, Press, Koenig, & Kinnealey, 2005) provided sensory integration therapy to seven children that included activities rich in vestibular, tactile and vestibular input and specifically addressed each child's individual sensory needs. Compared to behaviors following a simple tabletop activity, these children showed an 11% decrease in self-stimulating and self-injurious behaviors one hour after sensory integration treatment.

Addressing Sensory Processing Issues with a Family-Centered Approach

All of the above studies attempted to demonstrate the efficacy of specific sensory techniques, deep pressure in particular, on changing specific behaviors and are useful in documenting the success of these specific techniques in treatment. In early intervention, a family-centered approach is essential and the following studies will present this point of view.

Cohn, Miller, and Tickle-Degnan (2000) conducted a qualitative study on parental hopes for occupational therapy for children with sensory modulation disorders. Their study used qualitative interviews of five parents using grounded theory methods to explore parents' points of views about their hopes for the outcomes of occupational therapy using a sensory integration treatment approach. The children in the study ranged

in age from four to eight years. These parents identified three themes in terms of expected outcomes for their child's occupations: social participation, self-regulation, and perceived competence. The parents also identified two themes about what they wanted for themselves: strategies to help the child and personal validation as parents. Parents in the study wanted their child to develop behaviors and skills necessary for social participation or fitting in, belonging, and being included at school and in community settings. For themselves, the parents wanted to be able to support their child with strategies to help him/her. These parents also wanted to feel validated in their role as parents, and in being understood and accepted themselves. With this, coupled with the child's improvements in social participation, self-regulation and perceived competence, these parents felt that regular family routines would be facilitated.

In a later qualitative study, Cohn (2001) interviewed 16 parents to discuss their perspectives of occupational therapy using a sensory integration (SI) approach. These parents also reported that they sought SI treatment because their child was not fitting in, and accounted three changes in their child's function since beginning occupational therapy with an SI approach. The changes were in their child's abilities, activities and self-worth, and they stated that a change in one area dynamically affected the other areas of function. The parents also learned to reframe their expectations of the child. By gaining an understanding of their child's body functions and structures, these parents were then able to change activity demands accordingly. As activity demands were altered, these parents were then able to see improvements in their child's performance patterns and skills which then led to enhanced performance in many areas of occupation.

Progress in occupational performance in areas such as school, play, and social participation then led to the child's improved self worth. As these parents began to shift their understanding and expectations for their child and themselves, and they received validation of their parenting experience. They learned to support and advocate for their child. All of these changes led to parental perceptions of successful parenting.

Significance of the Research

Family-centered practice in early intervention is a philosophy that seeks to include families in decision making and develop services for the whole family and not just the child. This involves being guided by families' priorities for goals and services and offering and respecting families' choices regarding the level of their participation (Murphy et al., 1995). Family-centered practice provides help and support for the family, and not just the child. It is not provided in a clinic setting, but in the child's and family's own natural environment. Occupational therapists, as service providers, are consultants and collaborators with the family, in giving what is needed to help the child and family better function in their daily roles, routines, and occupations.

An essential component to family-centered, early intervention practice involves embedding positive parent-child and parent-therapist relationships into the daily rounds of family routines and occupations. The family provides the context in which the child most optimally develops. The infant is born into a family with certain innate body functions and structures that affect the parent-child relationship. Family members in turn provide a rich cultural, physical, social, spiritual, and temporal context that helps to shape the child's emerging behaviors. For occupational therapists, the Occupational Therapy

Practice Framework (AOTA, 2002) provides the structural model needed to support family members in finding what is needed for optimal functioning within the family unit.

Studies of typical family roles, routines and occupations have found that families use a variety of adaptive strategies to arrange and accomplish family occupations. Studies that examined roles, routines and occupations in families that have children with a disability found that these families also use a variety of adaptive strategies in their occupations, but they tend to use different strategies than those of families with typically developing children.

Sensory function in children may affect their ability to participate in daily routines and occupations, such as sleeping, eating, and self-regulation, and all areas of occupational performance. Infants who were born prematurely and infants with regulatory disorders process sensory information differently than normal infants, including how they processed deep pressure touch, integrated visual-tactile and ocular-motor information, and executed motor planning schemes (Weiner et al., 1996). Sensory processing issues also affect mother-infant interactions (DeGangi et al., 1997). Current best practice intervention for children with sensory processing issues focuses on occupation, and not on the use of specific sensory techniques. Therefore, any discussion of sensory processing issues or sensory diets (Wilbarger, 1995) should be embedded within the context of a child's and his family's daily occupational functioning.

Efficacy studies of treatment of sensory dysfunction thus far have focused either on a traditional sensory integration model applied in a clinic or school-based setting, or on a specific treatment technique, such as deep pressure or a weighted vest, on a limited

number of individuals (Edelson et al, 1999; Fertel-Daly, Bedell & Hinojosa, 2001; Neu & Brown, 1997; Olsen & Moulton, 2004; Smith et al, 2005). None of these studies were conducted in an early intervention setting, using a family-centered approach to provide intervention, in which the family's desires for success in their daily routines and occupations are considered. Most importantly, although sensory strategies and sensory diets are used widely by occupational therapists to address a child's function within family routines and occupations in early intervention, there has been a lack of research on treatment efficacy of sensory diets and in particular what specific activities should be encompassed in a sensory diet. This type of research has the capacity to inform current family-centered early intervention practice and to demonstrate what best practice is in supporting the child within the context of his family.

Purpose Statement

The purpose of this research was to explore parent and therapist perceptions of occupational therapy services in family-centered, early intervention, and specifically how sensory processing issues are addressed within family routines and occupations. These questions initially guided this research:

1. How do occupational therapists in early intervention define sensory diets?
2. What strategies do occupational therapists typically use with families, and why?
3. What sensory strategies are families using on a daily or routine basis?
4. How did occupational therapy assist in the development of the strategies that families use routinely?
5. How do these strategies fit into the family's everyday routines and occupations?

CHAPTER III: METHODOLOGY

Type of Study

This researcher used a phenomenological qualitative research method to explore the perceptions of parents and therapists in early intervention regarding sensory diets and their efficacy, particularly their goodness of fit within family routines and occupations. A specific focus in this study was on intervention methods currently used in early intervention to address the child's sensory processing issues within family routines and occupations. By using in-depth, open-ended interviews and field notes, the researcher hoped to describe what parents who had received early intervention services for their child with sensory processing issues perceived to be the strengths and weaknesses of their occupational therapy as it pertained to sensory diets, particularly in addressing their family's needs in regards to their daily routines and occupations. The researcher also hoped to garner from therapists currently practicing in early intervention how they determined what sensory strategies to use for sensory diets, why they chose to use specific strategies, and how they attempted to embed these strategies into family routines and occupations. The aim in using qualitative research methods was to focus not on collecting a certain quantity of insights, but on identifying or revealing a small number of themes of shared parent and therapist insights that reflected what they perceived as the

qualities or attributes of sensory-based occupational therapy services in early intervention (Patton, 2002).

Qualitative studies using a phenomenological method focus on describing the meaning of a *lived experience* for a group of individuals who have experienced a specific phenomenon (Creswell, 1998). It is a thorough examination of “how people experience some phenomenon – how they perceive it, describe it, feel about it, judge it, remember it, make sense of it, and talk about it with others” (Patton, 2002, p. 104). Using phenomenological methods, this researcher sought an understanding of what parents who had received occupational therapy services in early intervention experienced and how they interpreted the world for themselves and for their child differently after receiving these services. Therapists were also interviewed to collect their thoughts and views regarding what specific techniques they had used with the families interviewed. Phenomenological methods use *bracketing*, or the suspension of one’s beliefs to obtain phenomena in their pure and undoubted form, to attain holism (Gray, 1997). To set aside all prejudgments, the examiner stated her assumptions regarding sensory diets and then bracketed or suspended these presumptions to fully understand the experience of the subjects and not impose a supposition on the experience (Creswell, 1998).

An emergent design, or one where the design evolves over time as decisions are made in the field about where, from whom, when, and for how long to obtain data, was used. Qualitative designs are holistic, and strive for an understanding of the whole without making predictions about the phenomena studied. They take the researcher into and close to the real world so that the results and findings are grounded in the data.

Because of this, this type of design dictates that the researcher become intensely involved in the topic of study and become the research instrument, examining emergent themes and using inductive analysis to adapt the study design to the data that emerges over the course of the study. Reflexivity is the process of using self-awareness, political/cultural consciousness, and ownership of one's perspective in creating an authentic research instrument (Patton, 2002). So as not to cloud this research instrument with potential bias, the researcher prepared a self-as instrument statement before beginning data collection (Appendix A) and maintained a reflexive journal throughout the research. The reflexive journal was recorded in the personal section of the research log.

Qualitative research using phenomenological methods seeks to study issues in depth and detail, and typically produces a wealth of detailed information about a small number of people. This type of research seeks to reveal the full scope and nature of participants' feelings about what it was like to give and receive occupational therapy services in early intervention. Parents and therapists own words were used to express the depth of these feelings (Patton, 2002). The researcher used open-ended questions in the form of an initial interview guide (Appendices B and C) to gather rich, thick descriptions of parent and therapist perceptions of the use of sensory diet or sensory strategies in occupational therapy services in early intervention, and how these services addressed family needs in regards to daily routines and occupations. These interview guides evolved as the interviews progressed. The refined interview guides are found as Appendices D and E.

Sampling Plan

The researcher used purposive sampling methods, specifically criterion sampling. Criterion purposeful sampling concentrates on selecting the information-rich cases whose study will best elucidate the questions under study (Patton, 2002). In phenomenological studies, criterion sampling involves finding those individuals who have experienced the phenomenon (Creswell, 1998). In this study, the researcher sought therapists who had recommended sensory diets and families who had experienced them in early intervention.

Criterion sampling was used to identify key informants or gate keepers in these systems to target five therapist and four parent participants. Occupational therapists working in early intervention in urban and suburban areas of Virginia were solicited to participate in this study. Permission to contact these therapists was obtained from the therapist supervisor in each jurisdiction (Appendices F, G). The therapists were interviewed regarding their use of sensory strategies and sensory diets. They were then asked to identify one or two potential parent participants who had received occupational therapy services from them with a sensory focus. Solicitation or information letters (Appendix H) were then sent by the therapists to these families. A Call for Parent Volunteers information announcement (Appendix I) was also placed in a suburban Parent-to-parent newsletter. These purposeful sampling techniques were used to target information-rich cases for in-depth study. Criterion for selection of therapists included the following:

1. Therapist participants working in early intervention in urban and suburban areas of Virginia.

2. Therapist participants recommended sensory strategies and/or sensory diets in treatment.
3. Therapist participants received Virginia State sponsored trainings in working in Natural Environments and Family-Centered Practice.

Criterion for selection of parent participants included the following:

1. Parent participants were the parent of a child between the ages of one to five years who received occupational therapy services from one of the therapist participants in an early intervention program in a designated urban and suburban area in Virginia.
2. Parent participants received occupational therapy services to address their child's sensory processing difficulties, and sensory strategies were part of the treatment for these difficulties.
3. Participants were either English or Spanish speaking.
4. Participants received at least three months of early intervention services within the past two years.

Attempts were made to select therapist participants who use a family-centered approach in implementing their early intervention services and who had attended training in this approach provided by the Infant and Toddler Connection of Virginia. Therapist participants have attended these trainings since May, 2000 and the trainings have included topics such as: developing goals and objectives within family-centered early intervention, delivering services in natural environments, and designing services with a family-centered focus.

All of the parent participants who were targeted by the therapists had already transitioned from early intervention services and had done so within the past two years. These parents were not only more likely to have better recall of the services they received, but they were also more likely to have received family-centered services, because state support of this approach has been specifically augmented in the past four years. A three month length of therapy services was chosen as the minimum amount of time needed to establish a therapist-family relationship and for therapists to understand and to work optimally within family routines and occupations.

Access and Entry

This research proposal was submitted to the Institutional Review Board (IRB) of Virginia Commonwealth University following defense of the methods in December, 2004 and was approved on March 30, 2005. Five therapist participants were recruited through the early intervention programs in suburban and urban counties. Three potential parent participants were recruited by therapist participants, and the fourth through the announcement posted in the parent-to-parent newsletter. In the suburban county, the therapists called potential parent participants or showed them a copy of the solicitation letter (Appendix H) or a copy of the Call for Parent Volunteers that was posted in the county Parent-to-Parent newsletter (Appendix I). Permission was granted from the Occupational Therapy Supervisors in the two early intervention programs to do this (Appendices D and E). These parents were encouraged by the therapists to contact the researcher if they were interested in participating in this study. The informed consent

(Appendices J and K) also contained a statement that any participation in this study would not affect the quality of future services provided by their county.

When potential participants contacted the researcher to participate, a detailed description of the study and its requirements was discussed and given to the parents so that they were able to make an informed decision about their eligibility and willingness to volunteer to participate. Dates, times, and locations for interviews were then scheduled with the participants at a time convenient for them. A copy of the informed consent form was sent to each participant via electronic mail one to two weeks prior to the interview. The consent form was explained at the beginning of the interview and the participants were asked to sign it prior to engaging in the interview. A copy of the consent form is in the appendix (Appendices J and K).

Interview Settings

Therapist and parent participants were interviewed at the setting of their choice. Every effort was made to choose a location that was private and free of noise and distractions to ensure confidentiality and clear audiotaping. This was explained to the participants in the solicitation letter (Appendix H), in the Call for Parent Volunteers advertisement in the Parent – to – Parent newsletter letter (Appendix I), during the initial contact telephone conversation, and in the informed consent form (Appendices J and K). These letters explained time expectancy for interviews, number of interviews required, options for meeting places, the time frame of the study, and the therapist or parent option to withdraw from the study at anytime.

Role of the Researcher

The role of the researcher in this study was to gather detailed and information rich data from the participants. Establishing trust and rapport with the participants was key to this process. Treating each participant with respect and portraying an empathic and nonjudgemental attitude toward their responses was essential to developing trust and rapport. To extend this sense of courtesy and respect, thank you notes were also written following their participation.

The researcher prepared a self-as-instrument statement (Appendix A) to remain aware of and attempt to confront potential bias in this study. Extensive field notes were also written containing separate sections for observations, methods, personal insights and theoretical inferences. These field notes included a section for bracketing the examiners presuppositions of sensory diets, including how and why they might be used with families in early intervention. Discussion with thesis advisors and peer debriefing assisted in the development of theoretical inferences.

Data Collection

To gather rich, thick, descriptive and detailed information about therapist and parent perceptions of occupational therapy services in early intervention, in-depth face to face interviews and field notes were used. An interview guide (Appendices B and C) with open-ended questions and probes helped elicit therapists and parents to share their experiences in a candid and comprehensive manner, but also guided them in responding to the pertinent topic areas (Patton, 2002). The parent interview guide also included an initial demographic question for each family including the age of the child, diagnosis (if

any), dates of service, and specific services received. A separate interview guide was created for therapist participants (Appendix B) and parent participants (Appendix C). The therapist interview guide included an initial demographic question to gather information on years of experience, training in sensory integration or sensory diets, years of experience working in early intervention and and/or birth to three age group. The literature review and current gaps in research were used to guide the development of the questions for the interview guides. Nine interviews, five therapist interviews and four parent interviews, were completed to ensure sufficient gathering of quality information.

The initial therapist interview guide was field-tested with an occupational therapist working in early intervention who had used sensory diets while practicing in Virginia, but had recently moved to New York. The parent interview guide was field-tested with a Parent-To-Parent Coordinator in another suburban county in Virginia, whose own child with sensory processing issues had received early intervention services. A feedback form (Appendix L) was used to gather feedback on modifications needed. These interview guides then underwent further modifications, in terms of appropriate wording for the questions or probes to gather the most descriptive data from the participants. The interview guides were structured with earlier warm up questions to help put the participant at ease. This was also a time to gather demographic information (Lincoln & Guba, 1985).

Member checking was utilized in this study in two ways. First, the interviewer reflected back and clarified content during the course of the interviews. Second, all of the participants were formally asked to review the categories and themes that the researcher

compiled. The interviewer was then able to see that the participant perceptions fit what was described. These requirements were clearly stated in the consent form (Appendices J and K).

Data Management and Recording

All face-to-face and follow up telephone interviews were audiotaped. These audiotapes were immediately transcribed verbatim following the interviews. The written transcribed information was compared to the audiotapes for accuracy. Therapists were encouraged to invite both English and Spanish speaking families to participate, but no Spanish speaking families volunteered to participate in the study.

Detailed field notes were written following each interview. These field notes contained five types of information, divided into general information, observations, methods, personal, and theoretical sections. The general information section was dated and included where and at what time the interview took place, who was present, any physical descriptions of the setting and other details that might frame the context of the interviews (Patton, 2002).

The following sections of field notes separated direct nonjudgemental observations from interpretations and personal feelings. Observational types of field notes were used to record information such as detailed descriptions of the environment, including noise levels, difficulties with the environment, any difficulties with equipment, the participant's manner and demeanor throughout the interviews, their perceived comfort level, and detected signs of emotionality during the discussions. Methodological types of field notes were used to record changes made to the interview guide, or any other

issues that might arise pertaining to the methodological process of the interview.

Personal field notes included the researcher's thoughts on personal feelings that occurred during the interview, such as the researcher's emotional state and comfort levels prior to, during and after the interview itself, and also included thoughts on reflexivity, or the researchers' awareness of herself as part of the data that was being collected (Patton, 2002). This section continued the work begun as the self-as- instrument statement, helped to keep the researcher aware of her own bias, and contributed to bracketing the examiner's presuppositions from the participant's responses. A final theoretical or analysis log was used to record inferences and interpretations at every phase of the research process. These inferences were used to build theory directly from the data generated by the informants and also reflected the researcher's knowledge of the theoretical constructs from the literature review. The inferences were part of the data analysis and interpretation phase that occurs simultaneously with data collection and qualitative research. Discussion with thesis advisors and peer debriefing also assisted with the development of these interpretations.

Data Analysis and Interpretation

Once sufficient data was generated and all of the audiotapes were transcribed, the process of final data analysis began. The researcher began this process by examining the transcript and field note data from all of the participants. Statements were sought that explained how the participants understood their experience of occupational therapy, early intervention, and sensory diets and these significant statements were listed. Using a process called *horizontalization* of the data, each statement was treated as having equal

worth, and the examiner worked to develop a list of nonrepetitive, nonoverlapping statements. These statements were then grouped into *meaning units* or codes and the researcher listed these units, writing a description of the *texture* of these experiences (what happened), and included verbatim examples. Meanings were developed by spelling out the implication of each significant statement. These meaning units were then catalogued in a master code spreadsheet. Meaning units or codes were compared between therapists, between parents and between all of the participants to come up with common themes. Varying frames of reference were used during this process to construct a description of how sensory diets are experienced in early intervention. Finally, the researcher constructed an overall model of the process by which the knowledge of sensory diets is transferred from therapist to parent and how that transfer transforms the family. This model was then returned to the participants to ascertain if the model accurately recorded the meaning of their experiences and if the descriptions developed confirmed their personal experience (Creswell, 1998).

Rigor

Rigor involves intentional research design features and methods to minimize the threats to valid results. Trustworthiness of the data and findings from this study were addressed by looking at the confirmability, dependability, transferability and credibility of the data (Lincoln & Guba, 1985). In addition, a complete and thorough review of the research literature relating to this topic had been conducted prior to engaging in this study. Research advisors were also knowledgeable in the undertaking of qualitative studies and in the topic area of study.

Confirmability of data refers to its objectivity or neutrality, and this is assessed by seeking agreement of two or more people about the data's accuracy, relevance and meaning. Dependability of data refers to its stability over time and over varying conditions (Lincoln & Guba, 1985). This researcher gained confirmability and dependability of the data and findings by enlisting her research advisors to review the data collected, including the interview transcripts and accompanying field notes, as well as the codes and themes identified by the researcher. By using her advisors, confirmability and dependability of the data was addressed.

Transferability of data refers to its generalizability, or the extent to which the findings are transferable to other settings or groups (Lincoln & Guba, 1985). To accomplish this, the researcher sought to interview therapists and parents from one suburban and one urban area in Virginia. The researcher also attempted to find parent participants from a variety of ethnic and cultural backgrounds, to reflect the population of the county and the city and to have a more heterogeneous sample. Because the sample was dependent upon volunteers, it was not as diverse as desired. The parents who responded to the advertisement and solicitation letters were all from white middle class families. The results should, therefore, be considered in light of this relatively homogeneous sample. The use of thick, rich description allows readers to find similarities between the results of the study and their own situations.

Credibility refers to the believability of the results of the study (Patton, 2002). This was accomplished through peer debriefing and member checking. Peer debriefing was carried out by allowing a fellow graduate student familiar with qualitative methods

review the data and findings from the study as it progressed. Member checking was carried out throughout the study. Salient points were verified from the participants during the interviews themselves to ensure clarity of thought and ideas. This was done by repeating key answers to questions during the interviews to ensure that the researcher understood the full intentions and meaning of the participant's answers. Themes and assertions were also sent to the therapists and parents interviewed by electronic email and were then verified by phone to ensure that the participant's intent was captured. Participants recommended two slight changes to the wording of the themes and these were incorporated into the final themes.

Protection of Participants

This study involved minimal risk to its participants. Participants were asked to sign an informed consent form (Appendices J and K) prior to data collection, and were given a detailed description of the study when they receive the informed consent form. The study and all of its requirements were reviewed with each participant prior to asking for a signature. Participation was voluntary, and participants were given the option to withdraw at any time regardless of the reason. Participants were informed that participation in the study would in no way affect their current or future services supplied by their respective counties. Confidentiality was maintained throughout the study. All data, including audiotapes, transcripts, field notes, and personal data were kept in a locked file cabinet in the researcher's home to ensure confidentiality of the informants, and tapes will be destroyed upon completion of the study. Names were changed in the transcripts, demographic data and reports to protect participant confidentiality, as well.

Summary

This researcher proposed to use a phenomenological qualitative research method to explore the perceptions of parents and therapists in early intervention regarding sensory diets and their efficacy, particularly their goodness of fit within family routines and occupations. A specific focus in this study was on intervention methods currently used in early intervention to address the child's sensory processing issues within family routines and occupations. After reviewing current literature, it appeared that there was a lack of research that supported the efficacy of sensory diets used in occupational therapy practice using the family-centered philosophy of early intervention practice. Through the use of in-depth, open-ended interviews and field notes, the researcher aimed to describe what parents who had received early intervention services for their child with sensory processing issues perceived to be the strengths and weaknesses of their occupational therapy, particularly in addressing their family's needs in regards to their daily routines and occupations. The researcher also hoped to garner from therapists currently practicing in early intervention how they determined what sensory strategies to use for sensory diets, why they used specific strategies, and how they attempted to embed these strategies into family routines and occupations. The purpose of using qualitative research methods was to use open-ended interviews to gather information-rich data on shared parent and therapist insights reflecting what perceptions they have of the qualities and attributes of sensory-based occupational therapy services in early intervention. The researcher sought to reveal the full scope and nature of participants' feelings about what it was like to receive occupational therapy services in early intervention, and how these services

addressed their family's needs in regards to their daily routines and occupations.

CHAPTER IV: RESULTS

Data Collection, Analysis, and Presentation

The information presented throughout this chapter was obtained from in-depth interviews conducted with therapist and parent participants. A total of nine interviews were conducted, five with therapists and four with parents. One therapist was unable to identify a family to participate in the study. The therapists all worked in early intervention programs in urban and suburban areas of Virginia and had recommended sensory strategies and/or sensory diets in treatment. Parent participants were the parent of a child who had received occupational therapy services from one of the therapist participants to address their child's sensory processing difficulties, and sensory strategies were part of the treatment for these difficulties. Brief demographics on the participants are presented in Tables 7 and 8.

A remarkable feature of the therapist participants was the amount of experience, both as occupational therapists and as early intervention practitioners, each therapist brought to their intervention with parents. Years of experience as occupational therapists ranged from 9-27 years, and as early intervention practitioners, from 7-22 years. Considering the changes early intervention has seen in the past 10-15 years, it is a testament to the flexibility of these therapists to shift from a medical model to a family centered one.

Table 7. Characteristics of Therapist Participants

	Pat	Kay	Amy	Missy	June
Years of Experience as an Occupational Therapist	27	12	15	9	24
Years of Experience in Early Intervention as an Occupational Therapist	22	11	9	7	10
Suburban/Urban Setting	Suburban	Urban	Urban	Suburban	Suburban

Table 8. Characteristics of Parent Participants and their Children

	Nicky	Frances	Cindy	Betty
Suburban/Urban Setting	Suburban	Suburban	Urban	Suburban
Birth or Adoptive Order of Child who Received Services	first born	first adopted	fourth born	first adopted
Number of Children	2	2	4	2
Accompanying Diagnosis/Disorder	Autism Spectrum	None	Seizure Disorder	In Utero Drug-Exposure
Gender of Child	Male	Female	Male	Male
Time Elapsed since Discharge	7 months	23 months	3 months	14 months

All of the families who participated in the study had between two to four children, and the child who received early intervention services was the firstborn in three out of the four cases. Three were male and one was female. Two were adopted. Three of the children had accompanying diagnoses that have been associated with sensory processing disorders.

Approximately eight hours (7.95) of face-to-face interviews were conducted; three at participants' homes, four at food establishments, and two participants were interviewed at their workplace. Interviews were conducted using an interview guide and were audiotaped. One hundred and forty pages of transcripts were coded and analyzed. The analysis resulted in a model depicting how sensory diets became a "way of life" for families inextricably embedded in the routines of their everyday lives. Brief follow-up interviews were then conducted over the phone with each participant to ensure that the themes and assertions that arose from the analysis of the data were accurate and acceptable to the participants. This chapter will present the process by which this Sensory Diet "Way of Life" Model emerged from the data analysis and then will present the model itself with accompanying participant comments to support its authenticity.

Evolution of the Sensory Diet "Way of Life" Model

Analysis of the data began with the first participant interview by means of the use of field notes. Field notes recorded not only the logistics of where, when, and who was interviewed, but also included the participant's manner and demeanor throughout the interviews, and the researcher's thoughts on personal feelings that occurred during the interview. Field notes were also used to record changes made to the interview guide, helped to keep the researcher aware of her own bias, and contributed to bracketing the examiner's presuppositions from the participant's responses. A reflexive theoretical log was used throughout the analysis process to detail any interpretations of information obtained during the interviews, during transcription, and with coding of the transcripts.

Field notes were used early in the analysis process as an action that Dickie (2003) described as “housekeeping” – to sort, choose and order the data and “convert actions, sights and sounds into words and text” (p. 52) Shaping and bringing order to this data involved determining which pieces of information from the interviews were data, which required further exploration in later interviews, and which were extraneous information. These field notes guided changes to the questions asked during subsequent interviews. For example, the following is an excerpt from the reflexive theoretical log (Copeland, 2005):

After just listening to the Nicki interview, prior to interviewing Janet, I added the following questions to the parent questionnaire:

1. Do you see the sensory diet as a “way of life”?
2. Was the treatment geared towards you?
3. Did the treatment effect how you interacted with your child?
4. Did you feel like you got ‘enough’ occupational therapy?
5. Did your OT provide community resources?

These were the themes that seemed to pop out at me after listening to what Nicki said in the interview, before coding her thoughts.

She really talked about how after her therapy with Pat, she really saw the sensory diet as a “way of life,” it really became entrenched in their daily lives. She also talked about how the treatment was often directed at her, and not specifically toward her child (p. 4).

As expected in an emergent design, changes to the interview questions, such as adding probes and changing the wording of questions, were made in this way throughout the course of the participant interviews.

Analysis of the data in the reflexive field log guided changes to the initial research questions. The guiding questions for this research were: 1) How do occupational therapists in early intervention define sensory diets? 2) What strategies are they typically using with families, and why? 3) How are families using sensory diets on a daily basis? 4) How did occupational therapy assist families in the development of these strategies? 5) How do these sensory strategies fit into the family's everyday routines and occupations? The initial focus of the research was to define what occupational therapists working in early intervention believed constituted best practice with infants and children with sensory issues and to ascertain what sensory strategies families of these children found to be beneficial or of little or no value. As the interview guide evolved, the resulting questions yielded a description of how knowledge of sensory strategies was transferred from therapist to families and how these strategies truly became a "diet" for families, or a "way of life." The focus of the research became not about the efficacy of specific strategies, but about how those strategies change or transform the lives of the families of the child for whom they were prescribed. From the first interview, therapists discussed the family-centered approach and how this affected how they work with families. Intervention was not always directed toward the child or toward specific strategies that might help, but towards helping the family function more optimally with a child with sensory processing issues. Parents talked about how intervention was catered to their needs and how

therapists gave them a philosophy for living, and not just strategies. Much like the evolution of early intervention practice, it was as if the focus of the research questions shifted from a professional-centered view to a family-centered one.

After nine interviews, the decision was made to cease the data collection process as the researcher had sufficient data to proceed and further participants were not coming forward. Continued attempts were made to seek parents that might provide a different perspective, but no further participants volunteered. In addition, a similarity was emerging in some of the general responses that were being made by therapists and parents. Following the termination of the face-to face interviews, the researcher continued the process of data analysis by examining the transcript and field note data from all of the participants. Statements were sought that explained how the participants understood their experience of occupational therapy, early intervention, and sensory diets and significant statements were listed. These statements were then grouped into meaning units or codes and the researcher listed these units, writing a description of the texture of these experiences (what happened), and included verbatim examples. These meaning units will be referred to as codes throughout the remainder of this paper. Meanings of the codes were developed by spelling out the implication of each significant statement. These codes were then catalogued in a master code spreadsheet. Codes were compared between therapists, between parents and between all of the participants to generate common themes. Once a consistent group of themes was constructed, inferences were then created to loosely tie these themes into a coherent picture. Finally, an overall model of these inferences emerged describing the process by which the knowledge of sensory diets is

transferred from therapist to parent and how that transmittal of knowledge transforms the family. This model was then returned to the participants to ascertain if the descriptions developed confirmed their original experience (Creswell, 1998).

Participants recommended six slight changes to the wording of the themes and these were incorporated into the final themes and assertions. One therapist felt it should be included in theme one that sensory diets promote organization and self-regulation for a child's socialization as well as his or her development. Another therapist felt that, in theme two, she doesn't scan a family environment, but studies it in detail. She also recommended strategies based not only on a family's priorities, but on the family's goals for the child as well. Including siblings and peers was an addition that two of the therapists reported as crucial to both recommending strategies in theme two and generalizing ideas to new situations in theme five. One therapist thought it was important to pinpoint what a child is avoiding as well as what he or she is seeking when describing a child's sensory processing to parents. Finally, the therapists felt that getting a parent philosophically "on board" often comes last after the introduction of successful sensory strategies, not first, as originally thought.

Initial analysis consisted of loosely sorting statements into groups by similarities in the type of information they discussed. This loose sorting method is detailed in Appendix M. These groupings were later assembled more formally into codes with a description or definition of the information that permitted association with the code. There were 170 different codes in the initial coding list. For ease of viewing similarities and differences between the participants, participant names were color coded, with

therapist and corresponding parent given the same color. Aliases for the therapists were formatted in bold type to differentiate them from the parent participants. An excerpt from the initial coding list is presented in Appendix N.

Codes were compared between therapists, between parents and between all of the participants to generate the common themes. A preliminary grouping of themes was performed for the Institutional Review Board Continuing Review by scanning the master codes for codes in which the majority of participants contributed. The themes that emerged from scanning the master codes are presented in Table 9.

Table 9. Preliminary Grouping of Themes for Institutional Review Board Continuing Review

All Participants	Parents	Therapists
Favorite sensory strategies: Deep pressure <ul style="list-style-type: none"> ▪ Proprioceptive ▪ Oral motor ▪ Play with jumping on couch and with its pillows 	Unsuccessful sensory strategies: <ul style="list-style-type: none"> ▪ Weighted vest, blanket ▪ Brushing protocol 	Favorite sensory strategies <ul style="list-style-type: none"> • Prescribe deep pressure and proprioceptive strategies because they help children who are both hypo and hypersensitive
Sensory diet effects: <ul style="list-style-type: none"> ▪ Increased organization, attention, focus and self-regulation ▪ Improved interaction 	Family centered therapy: <ul style="list-style-type: none"> ▪ Therapist helped parent to help child direct own sensory diet 	<ul style="list-style-type: none"> ▪ Family centered therapy: <ul style="list-style-type: none"> ▪ Focus on family priorities and resources ▪ Problem solving is encouraged ▪ Parenting strategies given ▪ Need creativity to adapt strategies to the natural environment
Sensory diet definition: <ul style="list-style-type: none"> ▪ Activities incorporated into daily routines and occupations that include items in the home ▪ Activities designed to meet the child's sensory needs, improve sensory processing, and help child get and stay organized. 		

Data from the 170 codes were then grouped into 22 categories and those categories were examined in light of the original research questions. Supporting quotes were placed along with the category. These categories are detailed in Appendix O. To further strengthen dependability during analysis of the data, a second method of categorizing the data was used. After reading through each of the participant transcripts, information was gathered into “chunks” on post-its and similar idea chunks were placed in the same bundle. These bundles were then examined and defined with an overarching theme. Themes that emerged were separated according to which participant type, therapist or parent, expressed the idea. Six therapist and seven parent themes, with two overlapping themes emerged. These themes, along with supporting quotes from the participants, are found in Appendix P.

After generating themes using these two approaches to the data, the themes that emerged were re-examined, compared, and preliminary inferences were generated. A comparison of these inferences to the themes found in the preliminary theme groupings, the research question themes and the themes arising from the post-it method are found in Appendix Q.

Out of these inferences a pattern emerged. It became apparent that a process of knowledge transfer occurs in early intervention. It begins with the therapist bringing awareness of sensory issues to the evaluation of children and families. The therapist brings to each new client’s relationship a set of “lenses” that represents an informed perspective about sensory processing and sensory diets. Therapists find the right fit of activities to address the child’s sensory issues, and establish a relationship with the family

for transfer of knowledge about sensory processing and sensory strategies. As part of this process, the family's eyes are opened and their new awareness of their child's sensory processing is translated into action, with the ultimate goal of transferring that information to the child, who begins to be able to do his own self-regulation. This model answered a research question that emerged from the study "How does a sensory diet become a "way of life?" This question became the key question and focus of the study. The resultant themes that emerged from the categories describe the transfer of information from therapist to family. These themes are presented in Appendix Q.

The Sensory Diet "Way of Life" Model progressed through three versions before it developed into a form that was adequate for presentation to the participants. Some themes arose primarily from therapist comments, some from parent comments, and a third group arose from ideas shared by both and the later versions of the model reflected this. Both therapists and parents discussed aspects of how the family-centered model was utilized and how this helped ease the transfer of information. All of the participants described proprioceptive or heavy work strategies as the most useful. These common themes helped strengthen the concepts presented in the model. Ordering of the items was changed in later versions to better portray the flow of knowledge from therapist to parent and its resultant effects. For example, the theme: "Sensory strategies that are a "good fit" for the family become a "way of life" was initially the first item, but seemed to fit better at the end of the model and was therefore moved to the last item. Changes were made to the wording of the items to clarify meanings and describe what the participants were trying to articulate.

After discussion with thesis advisors, reexamining the data and further thought the model evolved further. It became a story that begins with the therapist's perspectives on why sensory diets help children and how to best set up the milieu to transfer this information to parents. The story then continues to describe how this information is transferred to parents in the words of both therapists and parents. As parents grasp the baton that is being handed to them about how their child processes sensory information, they come to an understanding of how they are to help their child, and the therapist then steps out of the story. Family life becomes possible because parents now have an understanding of how to generalize information about sensory diets throughout their routines and daily occupations and the therapist is no longer needed. These themes are compared to the initial model themes in Appendix Q.

To ensure the credibility of the model, the interim version was sent to all of the therapist and parent participants by electronic email and the themes were then verified by phone to ensure that the participant's intent was captured. The final model evolved from incorporating all of the participant comments that surfaced from member checking into the model and is presented in the final outline form in Appendix R. To communicate these themes in a more readable manner, a one page graphic model was created to show a picture of the passing of knowledge about sensory diets from therapists to parents and its resultant effects on the family. It is presented in Figure 2.

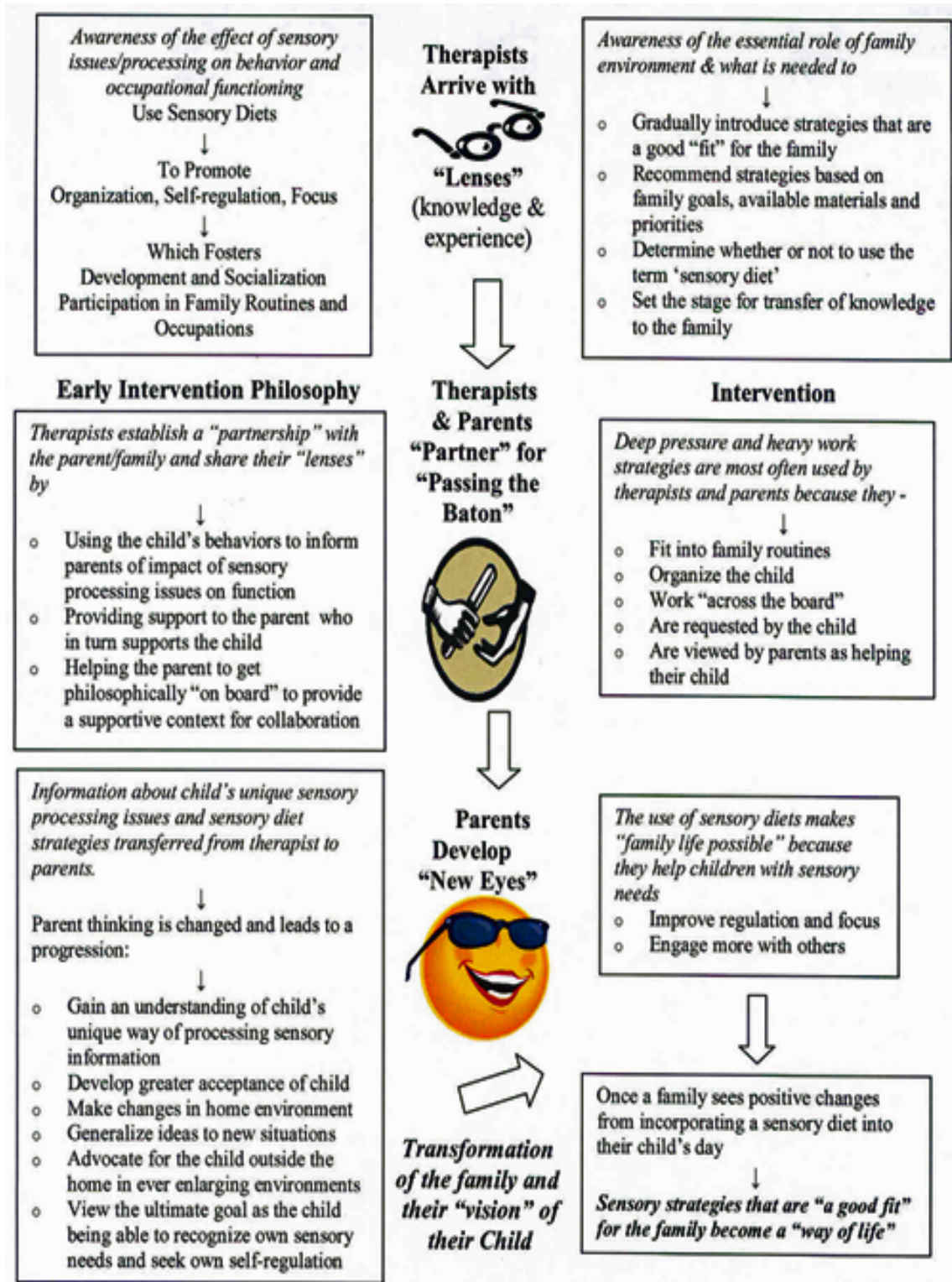


Figure 2. The Sensory Diet "Way of Life" Model

The Sensory Diet Becomes a “Way of Life”

The evolution of the Sensory Diet “Way of Life” Model came ultimately from what was said in the interviews by both therapist and parent participants in answer to the question “How does a sensory diet become a “way of life?” The remainder of this chapter will be devoted to the presentation of the model itself with accompanying participant comments to support its authenticity. The first two themes emerged from perspectives shared by the therapists and reflect “the lenses” therapists wear for the philosophical perspective derived from their knowledge and experience that therapists bring to the family environment of early intervention practice.

Theme One

Therapists Have an Awareness of the Effect of Sensory Issues/Processing on Behavior and Occupational Functioning

The first theme in the model arose from a therapist interview question: “Why do you use sensory diets?” All of the therapist participants talked about disruptive sensory based behaviors and how they interfere with family routines and occupations.

Assertion 1.1. The first assertion to arise from theme one was that **therapists use sensory diets to promote organization, self-regulation and focus**. Pat, a suburban therapist participant, reported that “often times – their child is running around, or fleeting from one activity to the next, or having a hard time being contained in a hug” and Missy, another therapist from the same county, stated that “I saw that the child had a lot of sensory needs – she had a very short attention span, she was bouncing off the walls, she was sensory seeking.”

Assertion 1.2. The second assertion to arise from theme one was **when therapists use sensory diets the child's development and socialization and participation in family routines and occupations is fostered.** The children therapists were visiting in early intervention were having a hard time sitting down and focusing attention on age appropriate activities. To address this problem, therapists prescribed sensory diets to help the child who was having sensory processing issues to sit down and focus on play activities and on socialization with family members, caregivers, and peers. Amy, an urban therapist participant, tells us that she uses sensory diets “to help kids get themselves organized so that they're in a better place to participate in activities and, and learn from what they're doing, and be able to develop their skills.”

Theme Two

Therapists Have an Awareness of the Essential Role of the Family Environment and What is Needed

All of the therapists used family-centered language when talking about how they went about the initiation of services with a family. They discussed how they used their first few sessions with a family to study, observe, and inquire about the family's daily routines and occupations, their home and community environments, and their supports and assets. June, a suburban therapist participant, commented how she tries to be observant of all aspects of the family environment, including what supports the caregivers have financially and socially. She then uses this knowledge to gauge how she presents any intervention strategies for the child. “It's probably a gut...observation of ... what the resources are – the emotional and energy resources are of the parent who's

there...[the more] their concerns about food and heating and clothing and all those things in there ... the slower I would go. I would give them one ...one thing to try.”

Assertion 2.1. The first assertion to arise from theme two was that **therapists gradually introduce sensory diet strategies that will be a good “fit” for the family.**

These therapists were resolute that family-centered early intervention involved taking time with families to get to know what their needs were and to bring in strategies at a pace that allowed parents to digest and incorporate them with little difficulty into their day.

It takes times to get – you know – to get to know the family – a little bit of time to kind of figure out what... they need to do and where exactly that they want to see the changes. And then, and then just trying to – to figure out where ... they go from there, and where really the issue is (Amy, a therapist from an urban area).

I don’t tend to provide a whole day’s worth of diet all at once... I tend to try to find one or two strategies to start with that seem reasonable and something the family’s interested in. And we pick the times to start with those strategies and then we may add things as that continues to grow (Kay, a therapist from an urban area).

Assertion 2.2. The second assertion to arise from theme two was that **Therapists recommend strategies based on family goals, available materials and priorities.** A tenet of family centered practice is to provide intervention in the child’s natural

environment, with the child's natural tools, and to provide this service with the family's goals and priorities for the child first and foremost in the therapist's mind.

We look at what the family is doing and what resources the family has – what their strongest interests are for the child...what they would really like that child to be able to do, to say, to think, to whatever. And we try and look within those parameters (June, a therapist in a suburban county).

Strategies are determined on what kind of input the child needs to focus, socialize and participate in family routines and occupations. Pat, a therapist in a suburban county, relates that “the goals in the program are written based on the challenges and needs that a family feels they have in relation to their child and their child's abilities and behavior.”

Providing early intervention in the child's natural environment involves not only working in the places where the child is most likely to play and engage in daily routines and occupations, but it also involves using the tools the child would naturally use and have available in those environments. These therapists discussed how they try to use what is already in the child's natural environment, and try not to bring or add a therapeutic item that isn't already there. Amy, a therapist in an urban area, was resolute that: “I don't take toys. I don't generally take things into a therapy session – into a home that I'm not – that I don't intend to leave there or you know, for them to try for awhile, or anything – I try to use what they have in the home.” Using what's available in the environment also means incorporating activities into typical routines. Missy, a therapist with a suburban county, shared that “I try to look at what a kid has in the house and what is typical in their routine and try to get – I try to look at what's around. I try not to bring in a lot of extra

stuff unless it's needed.”

The therapists related how many of the children they visited had difficulty with socialization with family members and peers; especially those with sensory processing issues related to an autism spectrum diagnosis. Providing sensory strategies that helped a child to be more receptive to touch and interaction was paramount for these families.

June, a therapist in a suburban county, reported that the sensory activities that she recommends are influenced by: “what it's gonna do for the child and how it's gonna help the parent-child relationship.” Activities should also enhance and support the child's participation in his interaction with peers and caregivers outside the home. Missy, another therapist from the same suburban county, stated that she attempts to find activities based on “how it will enhance the parent-child relationship and also relationships with others in the community – peers and caregivers.” She indicated that this community focus was particularly important when she qualified her response with “especially all the day care kids we see now.”

Assertion 2.3. The third assertion to arise from theme two was that **therapists determine whether or not to use the term ‘sensory diet’**. An aspect of being family-centered in early intervention practice for these therapists entailed whether or not to use the specific term ‘sensory diet’ with families. To establish a trusting relationship with the family, some therapists opted not to use the term because they thought it might have seemed too clinical, not culturally relevant, or not easily understood by a family. One strategy that therapists chose to use as an alternative was to label and describe the

specific sensation the child was seeking or avoiding with their behavior, rather than labeling it more generically as a sensory diet.

I think sometimes if I feel like they're being put off by the lingo then I don't. I just call it "sensory experiences" because I think the more, the more clinical it sounds, the more different it sounds –they kind of pull away. So I just kinda make it sound like – "oh, we all have our sensory needs," because we do. We all have – you know we – we figure out what we need to do to organize ourselves. (Missy)

Therapists found that labeling or describing the actual sensation the child was seeking or avoiding with their behavior helped parents to better understand their child's unique sensory needs. For example, in this quote, Kay shared that she describes proprioceptive vestibular input in understandable terms rather than using more clinical language with parents.

We talk about it being "deep pressure." We do talk about the senses and that there's more than just what you see, what you hear, what you smell. There are other senses – (and) that one of them is the sensation you get from hard work and it comes from your muscles. But, you know there's another sensation that we get and it comes from moving through space and I'll give them those names. (Kay)

Another approach that the therapists employed to describe sensory strategies without using the term 'sensory diet' was to focus on strategies and activities that would help improve the child's difficult behaviors. They discussed with parents how to decrease

some of the sensory based difficult behaviors that their child was engaging in on a regular basis. In this quote, again from Kay, she explains how she translates sensory diet information for parents into specific suggestions for their child.

For other parents, we just talk about the basics of what we're putting into their day and why it works. "You know, Johnny really, really needs deep pressure – he really needs that information he gets when his muscles are workin' hard. Let's talk about some ways that we can put that as part of your day"...I try and point out strategies – the things that I already see a child doing to compensate. You know, "you're worried because he's knocking his sister over, but all he's really trying to do is get that information as he gives her a hug and he just doesn't know where his body is." So, you know, "we can help him figure that out." So we talk about the things that we're already seeing in the child.

Assertion 2.4. The fourth assertion to arise from theme two was that **therapists set the stage for transfer of knowledge to the family**. An important component to providing family centered services to families involves studying the family environment, gradually introducing strategies, recommending appropriate activities for the child and family, and determining the appropriate type of language to use when presenting information. All of these methods help therapists set the stage for the transfer of knowledge about sensory diets and sensory strategies to families.

The first two themes emerged from perspectives shared by the therapists and reflect "the lenses" therapists wear for the philosophical perspective that therapists bring

to the family environment of early intervention practice based upon their knowledge and experience with sensory processing disorders. Themes three and four emerged from the perspectives of both the parents and the therapists. They address the relationship building aspect of family-centered early intervention practice that sets the stage for the eventual therapist “passing of the baton” of knowledge of sensory processing and sensory strategies to parents.

Theme Three

Therapists Establish a “Partnership” with the Parent/Family and Share their “Lenses”

These therapists embraced family-centered practice by forming a “partnership” with parents. With equal participants working together to help the child, the therapist imparts knowledge about sensory processing and helpful specific sensory strategies that they have found through their experience with other children and families. Therapists remarked that when they first began working with a family, they sought building this type of collaborative relationship with the family from the point of their initial contact with the family. This “partnership” is an essential component of the early intervention philosophy of collaboration, consultation and education. The stage has been set for the transfer of knowledge from the outset of the relationship.

Assertion 3.1. The first assertion to arise from theme three was that **therapists use the child’s behaviors to inform parents of the impact of sensory processing issues on function.** Therapists related that the first step in establishing a relationship with families involved identifying for families where the problem areas were for the child in terms of

their participation in family routines and occupations, and offering assistance where it was most needed. June described it as:

When they're touching something that they don't...like, or that they play with very briefly and then they look like they have that kind of "yucky" feeling, as I explain to parents ...do a hand squeeze... and then hand clapping to... decrease the...yuck feeling as I explain to parents...and then they'll often ... try things again.

Therapists related that parents didn't seek early intervention services because they suspected that their child had sensory processing issues. They sought intervention because their child was exhibiting some behaviors that were indicative of delays in development, such as a speech or fine motor delay, or their child was having difficulty with age appropriate functional tasks, such as eating, sleeping, or dressing. The child's atypical or difficult behaviors led them to seek help. Identifying and addressing these difficult behaviors is often a good starting point for therapists to begin the process of establishing rapport and a "partnership" with the parents. June shared that she needed to "look at the difficult behaviors for the family. They're looking at behaviors – so that's what I'm looking at, too, Giving parents observations – what to look for. (I) want them to feel positive and take charge and handle it and not be overwhelmed."

Another good starting point in establishing a relationship with families is to show them what sensory input the child is seeking or avoiding with their behaviors. Amy informed us that she prefers to "build on what the child likes to do already...use (the) child's behavior to show parents what input child needs" and Kay related that she often

chooses to “point out to parents – the things I already see the child doing to compensate...I can tell it’s working by the behavior changes that I see.”

Assertion 3.2. The second assertion to arise from theme three was that **therapists provide support to the parent who in turn supports the child.** Both therapists and parents commented on this theme. This theme marks the beginning of the transfer of knowledge, the metaphorical “passing of the baton,” from therapist to parent. Therapists discussed how they provided support to the parents in carrying out their daily routines and occupations with a child with sensory processing issues. Therapist Kay illustrated this when she said “As we work with children we just kind of tend to sit down and we’re talking about what I’m doing and what’s been hard in their day and what’s causing problems and through those conversations we begin to discuss strategies and we’ll try some of them right there.”

Parents related how this information sharing and support of their parenting abilities helped them to in turn support their child, through problem solving his specific needs, empowering him, or advocating for him. Nicky (the mother of a preschool aged son with an autism spectrum diagnosis) described her experience with her occupational therapist in early intervention in the following way.

So Pat was – Pat was an absolute lifesaver – for me at that time – really a tremendous support, for me and ... guiding me in directions of what resources to look at, um, you know – supporting me again in my mothering, but also in my, you know, advocating for him...A lot of therapy I think initially was geared towards me. ... There were lots of weeks that she

came and Jason just sort of did his thing and she and I just talked about how he needed a mom who wasn't going to pity him, and who wasn't going to sort of enable a disability by doing everything for him, and, you know, who was going to challenge him to be what he, you know, he's certainly capable of being.

This support of parents could be related in the global way that Nicky described or it was as simple as providing the needed reassurance as Cindy, a mother of a preschool aged child with a seizure disorder, portrayed it. "Now, sometimes it wasn't a strategy as 'a pat on the back' of – you're doing the right thing, it'll get better, he's making improvements, 'hang in there' kind of stuff, you know." An important aspect of this parent support was that it helped give these parents the assurance, confidence and energy they needed to in turn support their child. Nicky described it as "She showed us how to empower him – challenge him to be what he was capable of being." Betty, the adoptive mother of a preschool aged child who had in-utero drug exposure, explained that "June [her occupational therapist in early intervention] showed me ways I could do things differently by me guiding the hugs and physical activities...I helped his environment...Therapy required me doing things specifically in a certain way to help him." Frances related that "the goal was to teach me to interact with my child and help her and it worked." This new sense of enhanced control over their situation helped parents to gain the strength and energy to begin to verbalize and advocate on behalf of their child outside the home. An improved awareness and knowledge of their child's sensory needs and the ways to address them gave parents increased confidence and a

voice for advocacy on their child’s behalf. Cindy expressed that she “was able to easier verbalize his concerns, issues and needs to caregivers” and Nicky shared that it “inform[ed] the way we talk to people who we rely on to take care of him.”

Assertion 3.3. The third assertion to arise from theme three was that **therapists help the parent to get philosophically “on board” to provide a supportive context for collaboration.** Therapists related that parents needed to see that sensory strategies worked for their child before they would ask for a rationale as to why these strategies worked. The first step was to give them the knowledge of their child’s unique sensory processing abilities, and after parents understood how and why these strategies worked, they were more likely to be accepting of the sensory diet approach of providing sensory strategies to ameliorate sensory based behaviors.

Most people are like – I just want this behavior to stop – I don’t care how you’re going to do it and so we start some things that help them help his behaviors and once that starts – then – they’re interested in why, because it’s working. At least that’s been my experience. The kind of theory comes later. Ok, if this works, ok, now I get it – now I’d like to know why its working (June, a therapist with a suburban county).

Once a “partnership” is established between the therapist and the family and the family gets philosophically “on board,” that sensory processing and behavior are linked; families are open and ready to test sensory strategies with their child. Amy, a therapist in an urban area related that “well ... I think that one of challenges is...well you gotta get parents on board number one.” June, a therapist in a suburban area conferred “but you

have to have a parent on board or it doesn't work.” With a beginning understanding of how their child's sensory processing affects their child's routine and daily behaviors, families are willing and ready to try new sensory approaches.

Theme Four

Deep Pressure and Heavy Work Strategies Are Most Often Used by Therapists and Parents

Across the board, all of the participants, both therapists and parents, discussed how they used deep pressure and heavy work strategies to accomplish their goals and meet their child's needs. Therapists recognize the therapeutic value of proprioceptive strategies and make use of them routinely in their sensory diet recommendations. All the parents commented that they were still using these strategies after their early intervention services were discontinued.

Assertion 4.1 The first assertion to arise from theme four was that **deep pressure and heavy work activities fit easily into family routines**. One of the reasons for the strong favor of deep pressure and heavy work strategies for parents was their ease in implementation into family routines and occupations. Therapists identified a plethora of ways to adapt home and community activities to incorporate a deep pressure or heavy work component to them.

We talk about using blankets and wrapping or kind of swaddling a child for times to calm (him) and you know, we talked about that as a way that you can incorporate other activities. You know, that that can be your story time and they can get their – their sensory needs met and you can have

a nice quiet time. (Kay, a therapist)

In addition to adapting the child's routine play activities for optimal participation, therapists also discussed how they adapted daily routines to add deep pressure and/or heavy work input to ensure that the child received this needed sensory input throughout the day. Therapist June shared that she looks for:

Something that fits into their day – like the towels rub or rollup after the bath or another kind of activity that would be a natural, um thing for mom... And another one – pushing laundry baskets with things in them, pushing something heavy, putting the push toys on the grass or on the rug instead of on the floor because it's heavier work.

Likewise, parents described ways that they provided deep pressure and heavy work activities for their child throughout the day within their daily routine. Nicky, the mother of a preschool aged child with an autism spectrum diagnosis, related how she integrates sensory input into her son's daily routines by:

Incorporating him in the chores and things, but in ways that really – You know – enrich, or feed his, you know – to use the “diet” metaphor – his need for input. So, pushing, pulling, you know – he's the one that does the job of carrying the bags from the car to the refrigerator when we bring home groceries, for example.

Frances, another parent with a preschool aged daughter with sensory processing issues, recounted how her daughter needs time to be active everyday and because of this, she tries to incorporate heavy work and proprioceptive strategies into her daughter's day.

We need to get out of the house, either in the morning or the afternoon... she just can't handle the same surroundings....Just, running, she loves to run...The huge thing that was great for us was when she started riding her two wheel bike with training wheels. Because I just bought her this steel heavy bike because I figured the harder she had to work – the more proprioceptive input she would get.

Betty, a mother of a son with sensory processing issues, shared that the heavy work strategies became embedded in their routines because they were helpful and easy to use.

What's interesting to me is how much they (have) become part of the routine without even – trying to make it so – just because they were so helpful... Yes, and a lot of 'em are natural – you know, they're just fun things you come up with doing anyway on a day to day basis.

Assertion 4.2. The second assertion to arise from theme four was that **deep pressure and heavy work activities are organizing to the child**. Therapists use deep pressure and heavy work strategies because they help children to get organized so that they are able to participate in family activities.

Most of the strategies that I've used here ... I use to ... provide deep pressure, deep proprioceptive input to help children stay organized. ..for many of the families when we use massage as a way – the deep pressure that massage gives ... for some parents it's been – it's the first time that their child will sit down with them. (Pat, a therapist)

Assertion 4.3. The third assertion to arise from theme four was that **deep pressure and heavy work activities work “across the board.”** Therapists like to use deep pressure and heavy work activities because they work for children who are both hypersensitive and hyposensitive to sensory input. Missy, a therapist in a suburban county, explained it this way: “For the kids who need it, who are hypo responders and the kids who are hyper responders. It just seems to be a modulating – across the board effect.”

Assertion 4.4. The fourth assertion to arise from theme four was that **deep pressure and heavy work activities are requested by the child.** Parents report that they use deep pressure and heavy work activities because their child often requests them. Betty, a mother of a preschool aged child who was drug-exposed in utero, talked about how her son would either ask for help with an activity when he needed sensory input or ask to go outside where he could engage in pushing his cars, a heavy work activity.

Because he’s the one asking me to do the stuff ...he’ll say – come on – let’s build – let’s build a fort, let’s build a tunnel – build a tunnel today... And he loves to go outside. You know, and usually – we have a backyard, but he prefers to go outside to the front yard and do the whole thing on the driveway [pushing his cars], up and down and up and down and up and down and up and down.

Assertion 4.5. The fifth assertion to arise from theme four was that **deep pressure and heavy work activities are viewed by parents as helping the child.** Most importantly, parents have incorporated deep pressure and heavy work activities into their

routines with their child because they have found them to be helpful in assisting their child to organize for participation in family routines and occupations. Betty, a mother of a son with sensory processing issues, shared: “what’s interesting to me is how much they become part of the routine without even – trying to make it so – just because they were so helpful.”

The remaining themes, themes 5, 6, and 7, all emerged from parent responses. The therapist has entered the life of the family, shared knowledge, provided support to the parent, and encouraged problem-solving. The transfer of knowledge has occurred, and it is now up to the parents to generalize this knowledge and use it to better the life of their child and the family.

Theme Five

Information about the Child’s Unique Sensory Processing Issues and Sensory Diet Strategies is Transferred from Therapist to Parents

Parents in this study discussed how the process of “passing the baton” of knowledge about their child’s sensory processing and sensory diets involved their learning to think about their child in a new way. New “lenses” (knowledge) can completely change one’s “vision.” Insight into their child’s sensory processing led to changes in how parents interacted with their child and with those in the child’s home and community environments.

Assertion 5.1. The first assertion to arise from theme five was that **information about sensory processing helps parents gain an understanding of their child’s unique way of processing sensory information.** Parents accounted that having an

understanding of how their child uniquely processes sensory information was a crucial first step to being able to make a peaceful homelife.

So that was the particular kind of way in which sensory processing issues affected our kid, you know, and that – we learned that very much through Pat – I mean in our own reading and research, but very much through our interactions with Pat and her observations of him and her initial assessment of him... What his sensory needs are – what specifically overwhelms him and underwhelms him. (Nicky, a mother of a preschool aged child with an autism spectrum diagnosis)

Assertion 5.2. The second assertion to arise from theme five was that **information about sensory processing helps parents develop a greater acceptance of their child.**

Another benefit of this transfer of information is that with knowledge of the child's sensory processing issues, the parents felt that they could better accept their child for who he was.

The other thing it (occupational therapy) taught us was not to apologize, and not to explain. Say this is our daughter – we love her and this is who she is and not say – well she's got these sensory issues, or she's got these speech issues. It's just-accept your child for who she is. And help her work with what she's got... that was a big step to make, just accepting her for who she is and not excusing it. (Frances, the mother of a preschool aged daughter with sensory processing issues).

Assertion 5.3 The third assertion to arise from theme five was that **information about sensory processing helps parents make changes in the home environment.**

Parents saw that to help their child to function within the family unit, certain adaptations needed to occur within the home environment. With these changes, the child was better able to participate in a functional way. The first adaptation was to give the child boundaries through setting up structured routines and to be proactive about transitions between activities.

One of the things that she [her therapist] had helped me with was the – and I've heard this just from – in children in general – is the importance of routine, of a consistent pattern of things – so that he knows what's coming and he knows what's gonna be next and then – and then there's time to transition from each thing to the next... another thing that is part of our daily routine – it's on an as-needed basis – but that ... concept of ... me getting down to their level – and doing the eye to eye thing and talking to him and often times accompanying that with hugs, big hugs ... just to kind of settle him down. (Betty, the mother of a preschool aged child with sensory processing issues)

Nicky, another parent, talked about how awareness of her child's limitations in terms of transitions and the proactive strategies that could be used to address periods of transition in the day were found to be useful.

He has a sensory, you know, a central nervous system that processes sensory information differently from other children. That there are tactics

that you can use to help him...organize and understand his world, but you're gonna have to work on it – it's not gonna come naturally, and he's not gonna grow out of it and it's not gonna come to him... I would say he is a much more, you know, organized, and we're much more, at least we are much more aware of those things that make him disorganized and how to help him with that.

For Frances' family adapting the home environment involved adding equipment such as a trampoline and trapeze bar so that her daughter had the opportunity to get her sensory needs met without jumping on the furniture or climbing the walls.

Erin was jumping up and down on the furniture so we borrowed the trampoline from early intervention, and that worked, so then we bought one... when she started literally climbing the walls, holding onto the rod in the closets, that's when we got the trapeze bar.

Several parents reported that for their child to get his sensory needs met, he needed to have physical activity every day so that he could participate functionally in his daily routines and occupations. Betty shared that:

June (her early intervention occupational therapist) had mentioned this – this helps –and he was always – I was always encouraging him to – let's go out and play with the (toy) cars. And what he'd do – he'd push the car all the way up to the top, and then he'll let it roll down to the bottom. It usually crashes into the garage door – no – with no harm done. As long as, you know, his sister's out of the way and his mother's out of the way.

Um, but that was – that’s one of his favorite things to do – and – and for some reason that seems to, um – he gets a real kick out of it. And from what June had said – that was a good thing for him – again, grounding him, you know, keeping him busy – keeping those muscle groups busy so that he could have a chance to regroup and focus later on.

Parent Nicky’s eyes were opened to the understanding that opportunities for sensory enrichment exist everywhere, and that finding and incorporating them into her son’s sensory diet was actually fun for her.

Just seeing different media I guess as an opportunity for an enriching sensory experience... The therapy helped me to understand that better, so that I could incorporate it... being able to identify opportunities for, um, sensory input in just regular things, and any old things... the tissue paper that... comes in... gift wrapping or something, that we immediately take that out and consider it as – “oh, this, you know, a toy, now” And so now we take that and store it and we think of an activity we can come up with – crinkling the paper, ripping the paper.

Assertion 5.4. The fourth assertion to arise from theme five was that **parents are able to and want to generalize ideas to new situations, including siblings and other children.** Parents talked about how they took their knowledge of sensory processing and strategies and applied it to the activities they came up with to meet their child’s sensory needs. Frances used her knowledge of what sensory input her child needed when purchasing a bike for her daughter. “I just bought her this steel heavy bike because I

figured the harder she had to work – the more proprioceptive input she would get.” Some even went beyond the child with sensory processing issues and even applied organizing sensory strategies to the needs of siblings and peers as well. Nicky recounted that she used her knowledge of sensory strategies with her younger daughter as well.

But I’ve used, you know, a lot of elements of his SI therapies ... with her (his sister), and what I know about sensory integration with her. .. so that’s another way ... applying it to subsequent children (laughter) Yeah, I do things with her – and things like beans – and you know – letting her play in a bucket of rice or whatever is something that is now commonplace. .. I would have never thought of – had it not been for Pat (her early intervention occupational therapist) – I would have never thought it was important ...but now we use it with her as well.

Cindy, a parent of a child with a seizure disorder who has sensory processing issues, incorporated the strategies into her evening routines with her three older children.

I mean I don’t say ok it’s time – except for... making sure we get exercise. I don’t say – ok it’s time to go jump on the bed now. It’s just...when we go upstairs at nighttime to take a bath – everybody, you know, the kids get undressed and they jump on the bed – it’s just what they do. And before we would have said no jumping on the bed, and now we say yes – jump, jump, jump, jump, jump. You know, because we know that it, it soothes them to do that.

Assertion 5.5. The fifth assertion to arise from theme five was that **parents advocate for their child outside the home in ever enlarging environments.** An interesting finding of the study was that as parents understood what their child's sensory processing abilities and limitations were, they were better able to relate these needs to caregivers outside the home. Parents were empowered by the process. Nicky shared that:

Pat [her Occupational Therapist] was an absolute lifesaver ...guiding me in directions of what resources to look at... supporting me again in my mothering, but also in my... advocating for him... I mean... it educates the way that we ... informs the way that we talk to people who we rely on to take care of him.

Assertion 5.6. The sixth assertion to arise from theme five was that **parents view the ultimate goal as the child being able to recognize his own sensory needs and seek his own self-regulation.** Every parent verbalized that their ultimate goal was to understand and learn about their child's sensory needs so that they could eventually teach their child to figure out what he or she needed and for them to be able to take care of their own needs independently. Part of this involved, as Betty related, encouraging the child to ask for sensory input when it was needed and appropriate for the situation.

Because he's the one asking me to do the stuff – You know... can we play chase? Can you put me upside down? ...He will be the one – I'll be sitting on the sofa and he'll come over to me and ... he'll have his head down here and he'll flip his legs up and then he'll say – pick me up upside down.

And once the child was able to understand what he needed, the expectation was that eventually he could begin to ask for it himself.

She[the therapist] just basically... taught us that idea of making sure that he receives – gets what he needs prophylactically, proactively every day, so that he would have those opportunities to organize himself and he could begin requesting those types of things for himself – bump, bumps or such. (Nicky, mother of a child with an autism spectrum diagnosis)

Theme Six

The Use of Sensory Diets in Occupational Therapy Early Intervention Services Makes “Family Life Possible” Because They Help Children with Sensory Needs to Function in the Family

Parents related that learning about sensory diets and incorporating the strategies into daily routines and occupations created significant changes in their child. The child was now able to participate in activities in a more functional way than he or she was able to previously.

Assertion 6.1. The first assertion to arise from theme six was **that parents confirmed that sensory diets improve their child’s regulation and focus for participation in family routines and self-help activities.** In particular, their child was now able to engage and focus in a variety of family routines and occupations at home.

I was surprised to find how much of it I was doing and didn’t know that this is where it came from. You know, because it has made his behavior better. Um, it definitely has made his behavior better... how much they

become part of the routine without even – trying to make it so – just because they were so helpful – like the transition time, like the having a very set routine that you don't vary from very much. Because then – he knows what to expect and he's able to...function better in the environment and...it makes a difference in his behavior. It's more calm. (Betty, mother of a preschool aged child with sensory processing issues)

Assertion 6.2. The second assertion to arise from theme six was that **sensory diets help their child to engage more with others within and outside the home.** Parents reported how their child's behavior had significantly changed and was now different outside the home and how he or she was much more functional in their participation in activities in the community.

And now – he is, you know, and now we're faced with a kid who... at three years and three months is – has been succeeding in a ... typically developing preschool, in terms of his behavior, in terms of his... learning little things and being able to join the – the circle... and sit at the table for a snack with his friends, and... make eye contact on a limited basis with them when really prompted. (Nicky, mother of a preschool aged child with an autism spectrum diagnosis)

The final theme emerged from the perspectives of the parents and was the most powerful finding of the study.

Theme Seven

Once the Family Sees the Positive Changes that Come from Incorporating a Sensory Diet into their Child's Day, Sensory Strategies that are a "Good Fit" for them Become a "Way of Life."

This is the envisioned end result of the transfer of knowledge about sensory diets from an occupational therapist to a family. The family incorporates knowledge of how their child processes sensory information into their daily interactions with him. Betty, mother of a child with sensory processing issues, shared that "what's interesting is how they became a part of the routine without even trying to make it so – because they were so helpful." This involves making changes to the child's natural environments, both in the home and in the community, and advocating for his needs to his caregivers. As family life becomes possible as the result of these changes, the family is able to use what strategies were most helpful, but most importantly to adapt and make adjustments as they go to help their child function optimally in his daily routines and occupations.

'Cause I think we've integrated them into our daily practice – that I don't even think of them necessarily as – as – as therapy anymore for him – you know, it's just part of our normal practice, you know, um. To letting him do things that we probably wouldn't have let other kids do – like the jumping, um, and the foods, making sure that we don't force things on him that...So, yes. I believe that we have fully incorporated a sensory diet into our lives. However, we didn't necessarily think about doing it. It just happened. (Cindy, mother of a preschool aged child with a seizure disorder)

This mother's discussion of the very natural and easy incorporation of sensory strategies into her family routines and occupations is a testimony to early intervention therapists' skill in finding the just right fit of strategies for the child and the family. Nicky, another parent, described that these adaptations are how the sensory diet became a "way of life" for her family.

It's just sort of gradually become a "way of life" – it's just something that we know helps our kid – you know, um. So, so we have incorporated it... just the sensory processing way of looking at things has definitely become a "way of life." So, you know, understanding his sensory processing picture has definitely become a "way of life" and has definitely helped me target the types of things that would be helpful to him and would be, you know, less than helpful to him. So that's definitely become a ... it's a part of Jason – it's not anymore, it's not ... his sensory processing picture, it's just who he is and how we live our lives.

Summary

In conclusion, this chapter sought to present the process by which a Sensory Diet "Way of Life" Model emerged from the data collected from the nine participants interviewed for this study. The model describes a process that begins with the therapist bringing the "lenses" of his or her awareness of the effect of sensory processing issues on a child's ability to function optimally to the early intervention relationship. Those "lenses" help him or her evaluate a child and the family's needs, find the right fit of activities to address the child's sensory issues, and set the stage for a "partnership" with

the family that allows for transfer of knowledge about sensory processing and sensory strategies. As part of this process, the family gains insight. Their eyes are opened to seeing their child in a new light. As Cindy said of the therapists she worked with “I think they were able to see Eric in 6 months easier than I was able to see Eric in 6 months” But with time she gained a “vision” of her child’s future that she lacked initially. The therapist passes the baton to empower parents who have a new “vision” of their child and their changed thinking is translated into action. As the child grows older, they begin to understand their own sensory processing and the “lenses” are passed from the parent to the child. The ultimate goal is for the child to monitor his own self-regulation. In the next chapter, the posited Sensory Diet “Way of Life” Model will be discussed in relation to its ramifications to current research on sensory diets and family centered early intervention practice.

CHAPTER V: DISCUSSION

Discussion of Results

In this study, ideas of therapists and parents in Virginia shaped a model that illustrates how family centered intervention is unfolding in early intervention within the state. The initial research questions of this study sought to examine the use of sensory diets in early intervention from the perspective of both the therapists who suggested them and the parents who used them in their daily lives. These questions evolved into a model that describes how occupational therapists in early intervention enter the homes of the families and establish a “partnership” with parents in addressing a child’s needs. Once this “partnership” is established, knowledge is transferred to parents who then transform their “vision” of their child as they transform their daily routines of family life. This transfer of knowledge empowers families to generalize knowledge of sensory processing and sensory diets to ever enlarging environments. Ultimately, the sensory diet becomes a “way of life” for families. This chapter will begin with a discussion of ways in which this model illustrates an evolution in the practice and dialogue that therapists and families are using to describe family centered, early intervention. Next, how the Sensory Diet “Way of Life” Model defends or counters current research on developing “partnerships” with families will be discussed. Finally, limitations to the study, implications for practice and implications for further research will be discussed.

The Move toward Embracing the Family Centered Model

Various studies investigating the meaning of family-centered intervention and the extent to which it was being implemented were completed in the early to late 1990's (Mahoney and Bella, 1998; McBride, Brotherson, Joanning, Whiddon & Demmitt, 1993). Therapists interviewed during this time period understood the change in focus from child to family, but their actual practice of this philosophy was still variable. Part of the problem was that therapists initially lacked the skills to provide family-centered services. Another difficulty was the variability in which these programs emphasized family-centered practice. In one study, 40% of services provided were home-based, 21 % were center based, and 38% were combined center and home based (Mahoney and Bella, 1998). The findings of the current study and a study by Leiter (2004) suggest that therapists in early intervention practice are more readily aligning themselves with family-centered tenets. In Leiter's study, all service visits were home based, and the communication and relationships between therapists and families were described as collaborative, with professionals acting as "conduits of knowledge" (p.838) for parents. These findings are consistent with the findings of this study as reflected in the Sensory Diet "Way of Life" Model. In this model, the therapist establishes a "partnership" with the family acting as a "conduit of knowledge" about their child's behaviors, to 1) inform parents about the impact of sensory processing issues on function, 2) provide support to the parent, and 3) get the parent philosophically "on board" to provide a supportive context for collaboration. "Passing the baton" involves helping the parent to see their child with "new eyes." In Leiter's study, early intervention therapists taught therapeutic

skills to parents to apply to their daily lives with their child. Small adjustments to the activities that a mother and child already engaged in were made. Similarly, in the Sensory Diet “Way of Life” Model, therapists study the family environment and identify resources to gradually introduce strategies that are a “good fit” for the family.

Rush, Sheldon and Hanft (2003) discuss the strategy of coaching for early childhood professionals to expand beyond their direct service roles and to better comprehend the benefit of improving a child’s ability to function in everyday environments. A coach and learner work together in “partnership” to help the learner reach specific goals, and the coaching relationship emphasizes three shared elements: observation, action, and reflection (Hanft, Rush, & Sheldon, 2004). A coaching relationship generates and possibly facilitates more developmentally appropriate interaction and activities than the traditional direct intervention medical model. According to what is known about family-centered practice, the coaching model aligns well with early intervention practice. According to the current study and the study by Leiter (2004), it appears that therapists and early intervention practitioners, at least those with experience, are moving closer to the tenets of this model. In both studies, therapists reported that they sought to build a “partnership” with parents. In this study, therapists took this one step further by explaining how this collaboration unfolded. They began this process by studying the family environment, or “observing,” as expressed in the coaching model. The observation period helped these therapists to understand each family system and to develop a collaborative relationship with families. During the “action” phase of coaching, therapists and families in this study worked collaboratively to generate sensory

strategies, using the child's difficult behaviors as a baseline. Parents would try a strategy modeled by the therapist during a session and report back the following week as to whether or not it was successful in ameliorating some of the child's difficult behaviors. The therapist provided support to the parent who in turn supported the child through a process of "reflection." This involved questioning and active listening to encourage the parent to problem solve their own solutions in finding the "just right" strategy for meeting their child's sensory needs while also fitting into their day. Similar to the collaborative coaching model, the Sensory Diet "Way of Life" Model that emerged from this study reveals elements of observation, action and reflection, and reflects the move in early intervention practice away from the medical direct intervention approach and towards a family-centered collaborative approach.

"Partnering" with Parents in Early Intervention

Why is "partnering" and collaborating with families so important? Research has found that the parent-child relationship is critical for child development (Mayer, White, Ward & Barnaby, 2002) and that the well being of the parent is just as important as the development of the child. Parents like support from people who are knowledgeable about child development, disabilities and services (McWilliam, Tocci & Harbin, 1993). Parent-staff bonding is essential for the process of early intervention to work, and as relationships are established between therapists and families, parents are more willing to try new behaviors, and they engage more readily in joint problem solving (Minke & Scott, 1995). Also, McWilliam (2000) has related that "The most important lesson for families to remember is that all learning occurs between sessions" (p.21). In the Sensory

Diet “Way of Life” Model, therapists are concerned with developing relationships with families by studying and trying to understand how an individual family system functions. Developing a relationship or “partnership” with a family takes time and effort, but it is essential if the transfer of knowledge and the routine incorporation of a sensory diet is going to occur. The family determines their goals and priorities for intervention as well as the pace that strategies are introduced. In this way, a “partnership” is formed that respects the uniqueness of each different family.

In the Sensory Diet “Way of Life” Model, forming a “partnership” begins with therapists using the child’s behaviors to inform parents about sensory processing and useful sensory strategies. Providing support to parents in terms of communicating and transferring knowledge of the child’s development, disabilities and services is important, but the parents in this study also appreciated the support of “a pat on the back ... you’re doing the right thing, it’ll get better, he’s making improvements, ‘hang in there’ kind of stuff” (Cindy, parent of a child with a seizure disorder). Washington and Schwartz (1996) found that this type of support in mother-therapist communication was important in fostering perceived confidence and competence in family members. It also added a dimension to the collaboration that occurred with goal setting and problem solving. In the Sensory Diet “Way of Life” Model, providing a supportive context for collaboration helped parents to get philosophically “on board,” the final dimension to strengthening a “partnership.” As parents become attuned to the role that sensory processing plays in behavior, and they observe the change in behavior possible from making sensory diet changes, they begin incorporating these changes with greater frequency and confidence.

Once this “partnership” is a working entity, the transfer of information becomes a more fluid process and the ideal that McWilliam describes of fostering learning between sessions becomes possible.

McCollum and Yates (1994) found that a supportive context is established when a triadic model of the therapist supporting the mother-child dyad is used. This supportive context then strengthens the parent-child dyad to foster skill development in the child. Parents in several studies saw their early intervention therapists as givers of emotional support and described the therapists as a friend or member of their family (Edwards, Millard, Praskac & Wisniewski, 2003; Leiter, 2004; McWilliam, Lang, Vandiviere, Angell, Collins, & Underdown, 1995; Washington & Schwartz, 1996). The comfort level that comes from this type of supportive relationship allows the staff member to then act as a “conduit of knowledge.” In the Sensory Diet “Way of Life” Model, this support leads to an openness to learn new information, and the parent is ready to attend to and process the transfer of information about sensory processing and sensory diets. In the metaphor of the Sensory Diet “Way of Life” Model, their eyes are opened and they see their child in a new and more accepting way. The therapists “lenses” have been successfully transferred to the parents and the baton has been passed.

“Passing the Baton”: Victim to Advocate

Families are transformed as they learn about sensory processing and sensory diets. This transformation led to a progression in parents, similar to Polkinghorne’s (1996) research where he presented the recovery of occupational functioning following impairment as a transformation from victimic to agentic life plots. When parents first

enter early intervention, similar to Polkinghorne's victimic description, they feel out of control in terms of their child's behaviors and are "oriented more toward avoiding negative possibilities than actualizing positive possibilities" (p. 302). They try to avoid situations where their child might act out or hurt themselves or others. As they begin to understand the sensory processing component behind their child's behaviors they are better able to accept the child. They begin making the positive changes needed to move toward an agentic life story, and they possess the practical wisdom to problem solve how to prevent negative behaviors and support positive outcomes to situations.

In this study, the progression from victimic to agentic life plots is presented in Figure 3. By gaining an understanding of their child's unique way of processing sensory information, parents develop a greater acceptance of their child. Gaining understanding through knowledge of sensory processing and sensory diets gives parents confidence to begin making changes in their child's environment and problem solve ways to generalize this knowledge to new situations. As they move into the agentic realm, they begin to advocate for their child outside the home in ever enlarging environments. Parents want to eventually move the agent role from themselves to the child so that their child will inevitably recognize his own sensory needs and learn to regulate and ultimately advocate for himself.

Pierce (2000) completed a study of mothers of typical infants and observed how these mothers learned to change and enrich their home environment to protect and promote their child's development. In the Sensory Diet "way of Life" Model,

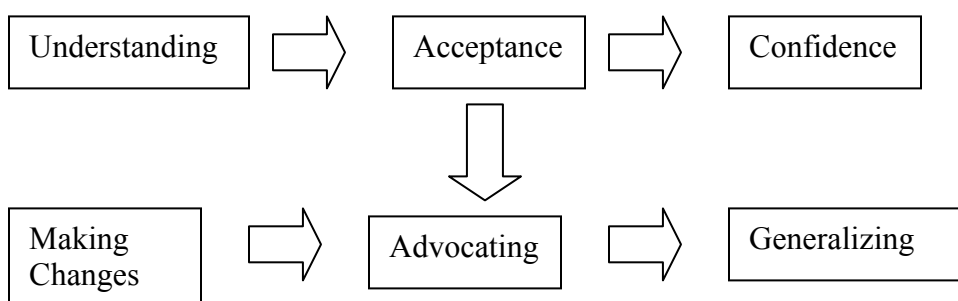


Figure 3. Sensory Diet “Way of Life” Model Parent Progression from Victimic to Agentic

parents seek the same objectives, and need to understand and accept their child’s needs before making these changes. Case-Smith (2004) found that parents believed that their child with a disability helped them to learn to appreciate and celebrate life and be more sensitive and tolerant of individual differences. They also learned from their experience of having a child with a disability to become a strong advocate for their child and other children with special needs. Minke and Scott (1995) encouraged staff members in early intervention to give control back to parents and empower them to make choices for their child to prepare for lifelong advocacy. Dunst and Dempsey (Dempsey & Dunst, 2004; Dunst, Boyd, Trivette & Hamby, 2002) found that a significant predictor of empowerment is associated with both relational (i.e., empathy, warmth, authenticity) and participatory (actively involving clients in identifying goals and courses of action) helping behaviors. Actively involving parents to participate in problem solving is essential to help parents feel empowered and able to move toward an agentic life story. These studies support the importance of parent motivation to make changes that support their child which in turn transforms how they see their life situation from feeling out of

control to becoming active advocates for their child. The Sensory Diet “Way of Life” Model then takes it one step further, to pass the empowerment on to the child, so he is now able to recognize his sensory needs, regulate himself, and eventually learn to advocate for himself.

Studies of families illustrated that parents seek to find ways for fulfillment despite their child’s disability (Larson, 2000) and that their child with a disability helped them to learn to appreciate and celebrate life (Case-Smith, 2004). Ultimately, parents want to be able to value the time they spend with their child and appreciate any support of this intention (Iverson, Shimmel, Ciacera, & Prabhakar, 2003). Parents in this study felt that the use of sensory diets by their occupational therapist in early intervention made their family life possible because it helped their child to be more engaged, regulated, and focused during family activities inside and outside the home. These families were then transformed by what they received from their early intervention providers. Not only did their outlook become empowered in how they planned and implemented their daily life activities for their child, but this way of thinking became “new eyes” that allowed them to envision their child’s future, a new “way of life.” For a therapist, seeing how strategies and modalities evolve into wellbeing and empowerment for families is invaluable. That’s when one truly sees the value of a family-centered approach.

Limitations of the Study

There are limitations in the generalization of these findings. The therapists interviewed were all very experienced, both as occupational therapists and as early intervention practitioners. In this study, therapists were sought who were trained in and

had successfully implemented sensory diets with families in early intervention. As a result, all of the therapists interviewed unreservedly believed in the efficacy of sensory diets and supported their use. As gatekeepers, they also targeted parents to be interviewed with whom they had connected and been able to transfer their positive experiences about sensory diets. Every parent interviewed made a commitment to try sensory strategies with their child and were successful in implementing sensory strategies in some way in their day. In the interviews, the therapists also talked about those parents or the child with whom they were unable to connect. For those families this model would look entirely different. The transfer of knowledge about sensory processing and sensory diets would not have been able to occur at all or not to the same extent and thus the outcome would most likely not look the same. It is presumed that these results are only generalized to therapist-family relationships where some sort of connection occurred.

As discussed previously, after nine interviews, the decision was made to cease the interview process as the researcher had sufficient data to proceed and further participants were not coming forward. Continued attempts were made to seek parents that might provide a different perspective, but no further participants volunteered. A limitation of this sample was that it was not representative of the diversity of cultures that abide in the counties where this study took place.

Another aspect that may have affected the outcome of this study is that one of the probes for one of the parent interview questions was to ask each parent if they felt that the sensory diet had become a “way of life” for them. This probe came out of analyzing the data from the first parent interview where Nicki reported that “The (sensory

integration) model has informed everything we do with him.” She talked about how her occupational therapist in early intervention taught her to look at her child’s behaviors as a result of his sensory processing issues. She also discussed that her OT taught her how to problem solve how to address those behaviors based on what sensory strategies might help him to be better regulated. Saying that the model informed everything she did expressed that it was entrenched in her daily life and had become a “way of life” for her. To see if other parents had this sense about sensory diets in their lives, this probe was added to the parent interview guide. Asking parents if they felt that the sensory diet had become a “way of life” shaped the outcome of this study in that every parent addressed this question in their responses and that information became data. Looking back at the actual transcripts, though, this probe usually came up after each mother had talked about what sensory strategies they were currently using, and how they had incorporated them into their day. In this way this probe was used more as an affirmation of what was already said rather than as a leading question. All of the parent participants were in complete agreement that sensory diets had indeed become a “way of life” for them.

Finally, as a therapist who works in early intervention and routinely prescribes sensory diets to families, the researcher has some bias about what strategies and approaches are most effective. Through strategies prescribed by qualitative research methods (Patton, 2002), the risk for bias and preconceived assumptions should have been significantly reduced. The methods employed in this study to reduce bias were: use of detailed field notes and memos to record personal reflections regarding the researcher’s subjectivity, biweekly consultation with advisors, peer debriefing with a fellow therapist

to verify the researcher's interpretations with an unbiased third party, and member checking with all of the participants to confirm and compare the researcher's interpretations of the resulting themes and assertions.

Implications for Practice

The Sensory Diet "Way of Life" Model describes a therapeutic process. Occupational therapists in early intervention enter the homes of the families they serve in early intervention and establish a "partnership" with parents in addressing a child's needs. Once this "partnership" is established, knowledge is transferred to parents who then transform their "vision" of their child and are empowered to generalize knowledge of sensory processing and sensory diets to ever enlarging environments. Very few studies in the occupational or physical therapy literature have described the actual therapeutic process. Various studies with adult populations (Brown, Humphry & Taylor, 1997; Clark, Corcoran, & Gitlin, 1995; Gyllensten, Gard, Salford & Ekdahl, 1999) have described modes of interaction with patients or caregivers that have the best patient outcomes or fostered optimal collaboration with caregivers. This research has not elaborated on how the actual transfer of ideas from therapist to client or family has occurred. This study illustrates how a family-centered approach with a collaborative "partnership" between therapist and family may lead to not only a transfer of knowledge from therapist to parent, but ultimately to a transformation of the family. Much research has investigated the value and efficacy of family-centered approach (Iverson, Shimmel, Ciacera, & Prabhakar, 2003; Mahoney & Bella, 1998; McBride, Brotherson, Joanning,

Whiddon & Demmitt, 1993; Shannon, 2004), but few studies have demonstrated a model showing not only family-centered intervention in action, but also its successful result.

An interesting aspect of the Sensory Diet “Way of Life” Model is that its focus is not on what sensory strategies are the most effective ones, even though parent and therapist participants had strong favorites that are mentioned in the model. Its focus goes beyond the actual strategies themselves and delves into the nature of relationships, how they are formed, and how this formation affects the prognosis for both the child and the family. Being able to explain how a family is transformed from a victimic life story to an agentic one is a useful tool for practice (Polkinghorne, 1996).

The Sensory Diet “Way of Life” Model worked in this study because the therapists that were interviewed for this study were highly skilled practitioners in the field of early intervention. They came with experience in early intervention practice ranging from seven to twenty-two years. These therapists commented on best practice for using sensory diets within a family-centered model. An important key to the development of sensory processing “lenses” is therapist education. All of the therapist participants had read extensively and attended workshops and courses on sensory processing and sensory strategies. They needed this strong knowledge base to act as a consultant on sensory issues to parents. These therapists also discussed the need for good interpersonal skills to develop a “partnership” with parents and were familiar with the coaching model as a way to instruct parents on ways to incorporate sensory strategies and sensory diets seamlessly into a family’s day. Another essential component of best practice for using sensory diets is to have well developed observational skills so that therapists can problem solve goals

and strategies for families as they unfold during intervention sessions. Observation skills are honed by having a clear knowledge and understanding of the routines and patterns of the family and all aspects of the environment, including cultural, physical, social, personal, spiritual and temporal aspects. By using these skills, these therapists were able to provide meaningful services to families.

Implications for Future Research

This study explored not only what sensory strategies occupational therapists in early intervention were routinely recommending to families and what strategies families were most likely using after intervention was terminated, but also how knowledge about sensory processing and sensory strategies is transferred to parents. Parents in this study commented about their initial unease with sensory strategies because of the lack of research supporting their efficacy. These parents came to trust that sensory strategies had efficacy with their child's behavior as they experienced the positive results of the sensory diet. Studies are beginning to fill this gap (Edelson, Edelson, Kerr, & Grandin, 1999; McIntosh, Miller, Shyu & Hagerman, 1999; Neu & Browne, 1997; Olson & Moulton, 2004; Smith, Press, Koenig & Kinnealey, 2005), but many more are needed to demonstrate to professionals outside the field and to our potential clients the usefulness of this theoretical framework and its modalities. An aspect of research on the provision of sensory diets in home environments that would be interesting to pursue would be to look at how therapists and their use of supplemental and therapeutic items in the natural environment evolves over time. Investigating when therapists feel that it is acceptable to introduce supplemental items within the natural environment would be an interesting

study. It would also be useful to examine the practice of less experienced therapists to see how easily they are able to “partner” with families, use a coaching model of instruction, and introduce sensory strategies and sensory diets so that families are able to incorporate them into their daily routines and occupations and become a “way of life” for them. In addition to this, it is also important to look at therapists and parents who reject or who are not receptive to the use of sensory diets to explore why they feel sensory diets don’t work, or why they feel sensory diets aren’t a “good fit” within their family’s routines and occupations. Further research that investigates the efficacy of the family-centered model and how it is utilized to help families and children in early intervention is also warranted.

Conclusion

This study sought to explore parent and therapist perceptions of occupational therapy services in family-centered early intervention and how sensory processing issues are addressed within the family’s routines and occupations. The initial study questions were: 1) How do occupational therapists in early intervention define sensory diets?; 2) What strategies are they typically using with families, and why?; 3) What sensory strategies are families using on a daily basis?; 4) How did occupational therapy assist in the development of these strategies?; 5) How do these strategies fit into the family’s everyday routines and occupations? These questions evolved into the Sensory Diet “Way of Life” Model which superseded the original questions. Upon completion of the study, the original research questions seem very limited in their scope and focus and the model surpasses them by describing the bigger picture. The model illustrates how occupational therapists in early intervention enter the homes of the families they serve in early

intervention and establish a “partnership” with parents in addressing a child’s needs. Once this “partnership” is established, knowledge is transferred to parents who then transform their “vision” of their child and are empowered to generalize their knowledge of sensory processing and sensory diets to ever enlarging environments. Ultimately, the sensory diet became a “way of life” for these families. As this study evolved, the results became less about sensory strategies and more about developing relationships to empower families. Cindy, one of the parents, discussed how her family has incorporated the sensory strategies for their son into their daily routines and occupations and feels that they are doing fine on their own with their sensory “lenses” in place.

But honestly I feel like ... I think we’re gonna get to a point where – like I feel like we’re doing fine on our own now. We’ve got a lot of strategies; we’ve incorporated a lot of things into our normal routines and into our home... and so he’s gonna do well I think.

As occupational therapists, it is extremely meaningful to see how strategies and modalities evolve into wellbeing and empowerment for families: it’s the ultimate goal of our profession.

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APPENDICES

APPENDIX A

Self-As-Instrument Statement

As I begin this research, I have identified factors that might affect my perspective on this particular course of inquiry. These factors include my employment as an occupational therapist working in early intervention with families of infants and children with sensory processing issues and my role as the mother of a young child.

My most important role is that of a parent. I know that my role as a mother strongly influences my work with children of special needs. I have experienced firsthand what it is like to raise a child, and especially how hard it is when my child is hurt physically or emotionally. I want him to have the best life has to offer. Being a mother has helped me to bond with the parents I work with, and have sense of commonality with them. I empathize with them as they go through the grief of a diagnosis, and then as they try to do what's best for their child.

Since coming to work in early intervention six years ago, I've felt a very strong sense of community with the parents I've worked with. They have welcomed me into their homes and their cultures. Often I've felt that I've learned as much from them as they from me. I have a strong bias toward many parents I work with in that I respect and admire the strength and tenacity with which they face the prospect of a child with a disability.

With 11 years of experience and expertise as an occupational therapist and six years as a professional working in early intervention, I often feel that I know what a child's needs will be: physically, developmentally, as well as what sensory areas need to

be addressed. It has been a challenge to make the shift from being a hands-on expert, to being a collaborator in family-centered practice. Because this model best meets the needs of families, I strive to practice it the best way I am able.

As an occupational therapist who has worked with many children with sensory processing issues, I have sought to learn treatment techniques, such as sensory diets to best meet the needs of the families I work with. I have strong biases about the effectiveness of particular sensory strategies, because I've seen children and families transformed when these strategies are implemented correctly. When a child is better able to handle what is coming into their senses, they are more readily able to engage in independent dressing, bathing, and feeding, and are better able to calm themselves in social situations, and when trying to fall asleep. Therefore, my bias is that I view sensory diets as valuable and would interpret data favorably.

These experiences potentially bias my judgment as a researcher in ways that are not intended. During the research, I tried to remain attuned to these biases and tried to avoid allowing these biases to influence the responses I made to participants during the research process. I attempted to "bracket" these biases in several ways. I sought to check my responses to participant verbal and non verbal responses to questions during the interview process. During data transcription and analysis, I used a reflexive journal to record and comment on my responses to the participants during the interviews and my thoughts on the evolving results from the data. This reflexive journal was also reviewed by my advisors to ensure that any biases were brought to my attention and discussed so as not to influence the results of the data.

APPENDIX B

Therapist Interview Guide and Questions

Criteria for Study

“Before we get started, I would first like to make sure that you meet the study criteria. Are you currently working as an occupational therapist in early intervention services in Virginia? Do you use sensory strategies and sensory diets in your practice? Do you use a family-centered approach?”

Probes:

- Definition of family-centered early intervention
- Agency therapist works for, if work for private contractor
- Length of time as early intervention occupational therapist
- Years of experience as occupational therapist
- Training in sensory integration or sensory diets

Sensory Diets: What

“Please define the term ‘sensory diet’. What strategies do you use that would fall under the term ‘sensory diet’?”

Probes:

- Sensory diet definition
- Specific sensory diet strategies

Sensory Diets: Why and How

“Why do you use sensory diets? Why do you use the specific strategies you mentioned? How are they helpful for families? Are they easy to implement? How do you incorporate these strategies into family routines and occupations? Can you give specific examples of when they were effective with families?”

Probes:

- more detail than above about education/training in sensory diets
- theoretical framework
- how/when determine scheduling of diets - awareness of family routines, occupations
- Effectiveness? (Examples)

APPENDIX C

Parent Interview Guide and Questions

Criteria for Study

“Before we get started, I would first like to make sure that you meet the study criteria. Is your child currently receiving, or did he/she receive early intervention services in Arlington or Fairfax County, Virginia? What services does or did he/ she receive? If your child is no longer in early intervention, how long has it been since services ended? Why did services end?”

Probes:

- Occupational Therapy, Physical Therapy, Speech Therapy, Educator
- Current Age of Child
- Age transitioned out of EI, length of time since services ended
- Perceived nature/limitations of disability/issues

Routines and Using Sensory Diets

“Tell me about a typical day with your child. Do you know what a sensory diet is? What sensory strategies did your OCCUPATIONAL THERAPIST teach you (as a sensory diet) to help your family manage your child’s daily routines and occupations?”

Probes:

- Routines: getting up, meals, dressing, hygiene, going to bed
- Family roles: mother, father, siblings
- Sensory diet: what it is
- Specific sensory strategies

Efficacy of Sensory Diets

“Do you currently use any of the sensory strategies your OCCUPATIONAL THERAPIST prescribed? Why? Do these strategies fit into your family’s routines and occupations? Do you recall any strategies that weren’t helpful?”

Probes:

- Specific sensory strategies
- Goodness of fit into daily routines and occupations
- Examples of helpful strategies in managing daily routines with child
- Ineffectual strategies

Satisfaction

“How has participation in occupational therapy in early intervention affected your family as a whole, and your family routines and occupations?”

Probes:

- Changes in routines, sleep, daily schedule
- Nature of play
- Self-care
- Child “fitting in” at community settings with other children: preschool, day care, restaurants, playground, Gymboree
- Changes in family relationships, roles

APPENDIX D

Revised Therapist Interview Guide and Questions

Criteria for Study

“Before we get started, I would first like to re-confirm on the audiotape that you meet the study criteria.”

- Are you currently practicing as an occupational therapist in early intervention in Virginia, or have you practiced in early intervention in the past two years? **Yes/No***
- How long have you been working in EI? _____ years*
- Do you use sensory strategies and sensory diets in your practice? **Yes/No***
- Where/how did you receive training on sensory diets? _____*

(Probe for (1) course focus: brushing, oral motor, therapeutic listening and (2) length of course)(3) specific sensory diet strategies gotten from course(s)

- Do you use a family-centered approach? **Yes/No***
- Did you receive state-sponsored training in natural environments? **Yes/No***
(Probe for: What does ‘natural environment’ mean to you as a therapist?)

Family-Centered Approach

“How do you define a family-centered approach? How does the family-centered approach influence your practice? Can you give one example of how you use a family-centered approach?”

Sensory Diets: What

“Please define the term ‘sensory diet’.

How do you define a sensory diet for your parents? Could you tell me whether or not you use the term ‘sensory diets’ with your families and what influenced that decision?

What strategies or activities do you use that would fall under the term ‘sensory diet’? Did you call this a “sensory diet” with your clients?

Probes:

- Sensory diet definition
 - when do you use it, when don’t you, and why
- Specific sensory diet strategies
 - eg. of how you explain to families why these strategies/activities might work with their children

Sensory Diets: Why and How

“Why do you use sensory diets? Why do you use the specific strategies you mentioned?”

Probe:

- Theoretical framework

Why do you think they are helpful for families – what changes did you see?

Probe:

- Any **Parent report** of noticeable changes in child’s behaviors and or parent relationship with child?

Do you feel that they are easy to implement? How do you incorporate these strategies into family routines and occupations? Can you give specific examples of when they were effective with families?”

Probes:

- How/when determine scheduling of diets
 - how many recommendations at a time?
 - provide written home program?
- How do you learn about family routines, occupations?
- Effectiveness? (Examples)
 - how do you tell if a sensory diet is working?
 - are there times that you don’t recommend a sensory diet – when and why?
 - do you change sensory diet recommendations – when and why?

APPENDIX E

Revised Parent Interview Guide and Questions

Criteria for Study

“Before we get started, I would first like to re-confirm on the audiotape that you meet the study criteria”.

- *“Your child is currently receiving (or did receive) early intervention services in Virginia, correct?” **Yes/No***
- *“What services does or did he/ she receive?”*
 - Occupational Therapy Physical Therapy Speech Therapy
 - Educator Other
- *“So your child does (or did) receive occupational therapy services to address his/her sensory processing difficulties, and sensory strategies as a part of his/her treatment, correct?”*
 - *definition of sensory processing difficulties if needed: difficulty in one of the following areas because of sensory sensitivities: eating, dressing, sleeping, play, bath time, or grooming*
 - *definition of sensory diet/sensory strategies if needed: activities your therapist gave you throughout the day to help your child better participate in activities of daily living, such as eating, sleeping, dressing, play, bath time or grooming.*
- *“Your child has received services in the past two years, correct?”*

Routines and Using Sensory Diets

“Tell me about a typical day with your child, including how you use sensory strategies throughout the day. (Fairfax County) Please describe what a sensory diet is. (Richmond) How do you use sensory strategies throughout the day?”

“What specific sensory strategies did your OCCUPATIONAL THERAPIST teach you (as a sensory diet) to help your family manage your child’s daily routines and occupations?”

Probes:

- Routines: getting up, meals, dressing, tooth brushing, bathing, going to bed
- Family roles: mother, father, siblings
- Sensory diet: what it is in their words
- Specific sensory strategies

Efficacy of Sensory Diets

What's working

“Describe how you currently use any of the sensory strategies that your OCCUPATIONAL THERAPIST recommended and why you use them? Describe how these strategies fit into your family's typical daily routines and occupations.”

What hasn't worked

“Are there any activities you'd like to be able to do, or do more of, but don't, because they don't fit into your daily life?”

Generalizations that work and don't work for them

“Please describe any activities or strategies that you came up with on your own”

Probes:

- Specific sensory strategies
- Goodness of fit into daily routines and occupations: eg. of helpful strategies in managing daily routines with child
- Environmental changes: bedroom, family room, outside play area, kitchen, bathroom
- Ineffectual strategies

Satisfaction

“How has occupational therapy in early intervention affected your family life?”

- family routines
- occupations?

“How has occupational therapy in early intervention supported your family life?”

“How satisfied are you in using these strategies? Can you give a 'before' and 'after' example?”

Probe for changes that have made life different in some way:

- Routines, sleep, daily schedule
- Nature of play
- Self-care
- Child “fitting in” at community settings with other children: preschool, day care, restaurants, playground, Gymboree
- Changes in family relationships, roles
- occupational therapist recommendations family centered?
- Strategies woven into natural environment?

APPENDIX F

Fairfax County Occupational Therapy Supervisor Agreement



Infant & Toddler Connection of Fairfax-Falls Church
 3750 Old Lee Highway, Fairfax, VA 22030
 703-246-7121 Fax 703-246-7307

Part of the Infant and Toddler Connection of Virginia 1-800-234-1448

Susan Sigler, Clinical Coordinator
 Infant and Toddler Connection of Fairfax

01/11/2005

Juliet Copeland, OTR/L

Dear Ms. Copeland:

I am writing this letter to confirm the details of our discussion regarding your research project: *Parent and Therapist Perceptions of Sensory Based Strategies Used by Occupational Therapists in Family-Centered Early Intervention Practice*. I would like to state that I agree to inform the occupational therapists in the Infant and Toddler Connection of Fairfax-Falls Church that you are interested in interviewing them about sensory diets and the sensory strategies they use with families in early intervention. I am aware that these therapists will target families they have worked with using these sensory diets and sensory strategies. The therapists will give me names of any potential families, and I agree to send letters to them asking if they would be interested in participating in your study. I also agree to allow you to contact the parent resource coordinator, Paula Gorman, to place an advertisement of your study in our newsletter. I have discussed with you that all of the parents participating in our program need to be ensured of their confidentiality, and that in order to do this at no time can I give you names of any parents participating in our program. I can only tell them of your study, and leave it up to them to contact you to participate. Finally, I am aware that you will be interviewing the parents who choose to contact you and that you will be discussing sensory diets and the sensory strategies they have received from their occupational therapist and how these sensory diets have fit into their daily routines and occupations.

If you have any further questions regarding your study, please contact me at 703-246-7164:

Sincerely,

Susan Sigler, Clinical Coordinator
 Infant and Toddler Connection of Fairfax-Falls Church

Providing Part C IDEA Early Intervention Services

Special Events - Outside The Church Community Services Bureau

APPENDIX G

Terry Izzo PT/PCS
Director, RARC Infant and Child Development Services

Date

Juliet Copeland OT/PT

Dear Ms. Copeland:

I am writing this letter to confirm the details of our discussion regarding your research project: *Parent and Therapist Perceptions of Sensory Based Strategies Used by Occupational Therapists in Family-Centered Early Intervention Practice*. I would like to state that I agree to inform the occupational therapists in Richmond Infant and Development Services that you are interested in interviewing them about sensory diets and the sensory strategies they use with families in early intervention. I am aware that these therapists will target families they have worked with using these sensory diets and sensory strategies. The therapists will give me names of any potential families, and I agree to send letters to them asking if they would be interested in participating in your study. I have discussed with you that all of the parents participating in our program need to be ensured of their confidentiality, and that to do this at no time can I give you names of any parents participating in our program. I can only tell them of your study, and leave it up to them to contact you to participate. Finally, I am aware that you will be interviewing the parents who choose to contact you and that you will be discussing sensory diets and the sensory strategies they have received from their occupational therapist and how these sensory diets have fit into their daily routines and occupations.

If you have any further questions regarding your study, please contact me at 804-358-1874.

Sincerely,

Terry Izzo PT/PCS
Director, RARC Infant and Child Development Services

APPENDIX H

Parent Solicitation/Research Description Letter

Susan Sigler, Supervisor
Fairfax County Parent Infant Education Program
Fairfax County, VA

(Date)

Dear (Parent):

An occupational therapist, Juliet Copeland, is a graduate student at Virginia Commonwealth University (VCU). For her graduate thesis she is conducting a study entitled *Parent and Therapist Perceptions of Sensory Based Strategies Used by Occupational Therapists In Family-Centered Early Intervention Practice*.

For this study Ms. Copeland is seeking parents of children who have received occupational therapy services in early intervention with a specific focus on sensory strategies and/or sensory diets. Families who participate can be English or Spanish speaking. She would like to ask your help in completing this study. She is looking for the following:

- Parents of children who have received or who are currently receiving occupational therapy in early intervention with a specific focus on sensory strategies and/or sensory diets.
- Parent of a child between the ages of one to five years who received occupational therapy services for at least three months.
- Parents will have received at least three months of occupational therapy services in early intervention within the past two years.
- Parents will be either English or Spanish speaking.

If you have checked the above boxes, she would like you to consider helping her with her study.

The purpose of the study is to find out what parents think and how they feel about occupational therapy services with a sensory focus in early intervention. She would like to know how you feel your occupational therapy services have benefited your child, ask questions about the relationship you have or had with your child's occupational therapist, and what sensory strategies your occupational therapist might have taught you to help your family manage your child's daily routines and occupations.

Juliet Copeland, an occupational therapist and graduate student at Virginia Commonwealth University (VCU) will conduct the study. Dr. Dianne Koontz Lowman, assistant professor at VCU, will direct the study. VCU's Committee for the Conduct of Human Research has approved the study.

Your participation would include being asked questions in your home or a location of your choice. Every effort will be made to choose a location that is private and free of noise and distractions to ensure confidentiality. The initial interview may last 60-90 minutes. The interview will be tape recorded but the tape will be destroyed after the study is completed. In the interview you will be asked questions about how you feel about occupational therapy, early intervention, your relationship with your occupational therapist, what sensory strategies your occupational therapist provided and how well these strategies fit into your family routines and occupations. You will also probably be asked to be interviewed again later over the telephone, in your home, or at a location of your choice. This follow up interview may last 60 minutes.

It is your choice to participate in this study. Your participation in this study is not associated in any way with your early intervention services, and whether or not you choose to participate will have no effect on your occupational therapy services, your early intervention services, or any other services you receive now or in the future through Fairfax County. You can withdraw at any time. All information that you share with Ms. Copeland will be confidential. Your name will be changed to protect your identity. If you choose to contact Ms. Copeland, you will be given more information about the study and answers to your questions. You will be asked to sign a consent form before the study is started. If you find any of the questions in the interview to be upsetting, you can choose not to answer them. This study has no risk to your physical health.

You may enjoy the chance to share your experiences about early intervention and benefit from the opportunity for retrospection. Your help in this study may provide important information that may help therapists who provide services and other families who receive them.

If you think you would like to take part in this study, please call Juliet Copeland, occupational therapist, at (703) 241-9791. Or write your name, address and phone number on the attached form and mail it to the address given at the bottom of the form. If you have any questions, please feel free to call Juliet Copeland at the number given above. Ms. Copeland hopes that you will give some thought to helping with this study. She looks forward to speaking with you if you choose to help out.

Sincerely,

Susan Sigler

PARENT STUDY REGISTRATION

Yes, I am interested in helping with the study:

Name: _____ Phone: (____) _____

Address: _____

Please mail this form to:

Juliet Coneland OTR/T

20111 14th St
170

APPENDIX I

CALL FOR PARENT VOLUNTEERS

Juliet Copeland, an occupational therapist and a graduate student at Virginia Commonwealth University (VCU), is conducting a study entitled *Parent and Therapist Perceptions of Sensory Based Strategies Used by Occupational Therapists In Family-Centered Early Intervention Practice*.

For this study Ms. Copeland is seeking parents of children who have:

- received or who are currently receiving occupational therapy in early intervention with a specific focus on sensory strategies and/or sensory diets.
 - a child between the ages of one to five years who received occupational therapy services for at least three months within the past two years.
 - Parents will have received at least three months of occupational therapy services in early intervention within the past two years.
- **** Parents may be either English or Spanish speaking.

She will ask how you feel your occupational therapist services have helped your child, ask questions about the relationship you have or had with your child's occupational therapist, and what sensory strategies your occupational therapist might have taught you to help your family manage your child's daily routines and activities

. Your participation would include being interviewed 1- 3 in your home or a location of your choice. Interviews may last 60-90 minutes for the initial interview and 15-30 minutes for any subsequent interviews. All interviews will be tape recorded but the tapes will be destroyed after the study is completed.

Participation in this study is the chance to share your experiences about early intervention, and provide information that may help therapists who provide services and other families, who receive them,

If you are interested in participating in this study, please contact Juliet Copeland, OTR/L at 703-241-9791.

APPENDIX J

Date _____

Initial _____

Page 1 of 4

Informed Consent Form

RESEARCH SUBJECT INFORMATION AND CONSENT FORM
Therapist Participant Form

TITLE: Parent and Therapist Perceptions of Sensory Based Strategies Used by Occupational Therapists in Family-Centered Early Intervention Practice

VCU INSTITUTIONAL REVIEW BOARD NUMBER: 4302

INVESTIGATOR: Juliet Copeland, OTR/L

This consent form may contain words that you do not understand. Please ask the above person/investigator to explain any words that you do not understand. You may take home an unsigned copy of this consent form to think about and discuss with your family or friends before making your decision.

Purpose of the Study:

The purposes of this research study are to:

- Define what sensory diets encompass in early intervention.
- Find out the thoughts and feelings of parents of children with disabilities about their occupational therapy services in early intervention.
- Find out what sensory strategies families are using on a daily basis and how these sensory strategies fit into the family's everyday routines and occupations.

You are being asked to participate in this study because you are a therapist working in early intervention that provides sensory diets to families.

Description of the Study and Your Involvement:

If you decide to participate in this research study, you will be asked to sign this consent form after you have had all of your questions answered and understand what will happen to you. In this study you will be asked to complete one interview describing your experience as an occupational therapist in early intervention using sensory diets within a family-centered model. Specific questions will be asked about what sensory strategies you use, why you use them and how easy or difficult you found these strategies were to implement within the family's daily routines and occupations. The interviews will be held at a time and place of your choosing. Every effort will be made to choose a location

Initial _____

Page 2 of 4

that is private and free of noise and distractions to ensure confidentiality. You may be asked to do a follow-up telephone or face to face interview. The interview(s) will be audiotaped and the audiotapes will be typed out so that the researcher can find ideas and themes from the thoughts that are discussed. After all of the interviews have been summarized, you will be asked to look at this to make sure that your ideas, thoughts, and/or feelings were correctly depicted. The audiotapes will be destroyed when the study is completed. The transcripts will not contain your personal identity.

At the first interview, the researcher will discuss the study purpose, ask questions to make sure that you meet the study criteria, review and discuss the consent form, and talk to you about yourself and your experiences in early intervention. You will be sharing information about your use of sensory diets within your occupational therapy practice and how you feel these strategies have affected the quality of the lives of the families you have worked with in early intervention. This interview will take 30-60 minutes. You will be asked for your address to mail the summary of the interview. If you decide to be in the study, you will be asked to sign this consent form after all of your questions have been answered.

A second interview may be done to clarify any thoughts or meanings that might not have been clear after the first interview. This interview will be over the telephone or at a location you choose and will be audiotaped.

The third contact will be by mail. In the mail you will receive a summary of the categories and themes from the interviews. You will be asked to look over the summary and add any comments to clarify meanings and make clear any misunderstandings. You will be asked to send back the summary with your comments in the envelope provided.

Risks and Discomforts:

This study was not proposed to cause any physical, financial, or mental risk. You may not derive any personal benefit from participating in this study. Development of questions for the interview will try to be open-ended, so that participants will not feel that it is necessary to discuss topics they may not feel comfortable in discussing related to their early intervention experience. Participation in the interviews will take some of your time and this may make scheduling difficult.

Benefits:

This is not a medical study, and there are no medical benefits to being in this study. You may not derive any personal benefit from participating in this study. You may indirect benefit from participating in this study, in that you will be giving helpful information about sensory diets and your experiences with early intervention.

Initial _____

Page 3 of 4

Costs:

There is no cost to be in this study. The interview will be scheduled at a time that will not interfere with your job or other commitments.

Alternatives:

This is not a treatment study. You can choose not to participate in this study.

Confidentiality:

We will not tell anyone the answers you give us; however, information from this study and information from the consent form signed by you may be looked at or copied for research or legal purposes by Virginia Commonwealth University. The investigator will treat your identity and information with professional standards of confidentiality. Your name, or the names of any persons discussed during the interview, will not be used in the summary or reports written from this study. The audiotapes used will be destroyed upon completion of the study. The information from this study may be presented at meeting or in publications, such as journals. Your identity will not be revealed in those presentations.

If an Injury Happens:

Virginia Commonwealth University and the VCU Health System (also known as MCV Hospital) do not have a plan to give long-term care or money if you are injured because you are in this study.

If you are injured because of being in the study, tell the study staff right away. The study staff will arrange for someone to care for you if needed.

Bills for treatment may be sent to you or your insurance. Your insurance may or may not pay for taking care of injuries that happen because of being in this study.

Voluntary Participation and Withdrawal:

You do not have to participate in this study. If you choose to participate you may stop at any time without penalty. You may also choose not to answer any particular questions that are asked during the study.

Questions:

In the future, you may have questions about your participation in this study. If you have questions, contact:

Student Researcher:

Juliet Copeland OTR/T

Initial _____

Page 4 of 4

Faculty Advisor:

Dianne Simons, PhD, OTR

Virginia Commonwealth University, Department of Occupational Therapy
(804) 828-2219

If you have any questions about your rights as a research participant, you may contact:

Office for Research Subjects Protection

Virginia Commonwealth University

800 East Leigh Street, Suite 111

P.O. Box 980568

Richmond, VA 23298

Telephone: (804) 828-0868

Consent:

I have been given the chance to read this consent form. I understand the information about this study. Questions I wanted to ask about study have been answered. My signature says that I am willing to participate in this study.

 Participant name printed

Participant signature

Date

 Witness Signature (**Required**)

Date

 Signature of person conducting informed consent

Date

 Investigator Signature (if different from above)

Date

APPENDIX K

Initial _____

Page 1 of 4

Date _____

Informed Consent Form

RESEARCH SUBJECT INFORMATION AND CONSENT FORM

Parent Participant Form

TITLE: Parent and Therapist Perceptions of Sensory Based Strategies Used by Occupational Therapists in Family-Centered Early Intervention Practice

VCU INSTITUTIONAL REVIEW BOARD NUMBER:

INVESTIGATOR: Juliet Copeland, OTR/L

This consent form may contain words that you do not understand. Please ask the above person/investigator to explain any words that you do not understand. You may take home an unsigned copy of this consent form to think about and discuss with your family or friends before making your decision.

Purpose of the Study:

The purposes of this research study are to:

- Define what sensory diets encompass in early intervention.
- Find out the thoughts and feelings of parents of children with disabilities about their occupational therapy services in early intervention.
- Find out what sensory strategies families are using on a daily basis and how these sensory strategies fit into the family's everyday routines and occupations.

You are being asked to participate in this study because you are the parent of a child who receives or who has received early intervention and occupational therapy services.

Description of the Study and Your Involvement:

If you decide to participate in this research study, you will be asked to sign this consent form after you have had all of your questions answered and understand what will happen to you. In this study you will be asked to complete one or more interviews describing your experiences in early intervention with your occupational therapist. Specific questions will be asked about what sensory strategies were taught to you and how easy or difficult you found these strategies were to implement within your daily routines and occupations. The interviews will be held at a time and place of your choosing. Every effort will be made to choose a location that is private and free of noise and distractions

Initial _____

Page 2 of 4

to ensure confidentiality. You may be asked to do a follow-up telephone or face to face interview. The interview(s) will be audiotaped and the audiotapes will be typed out so

that the researcher can find ideas and themes from the thoughts that are discussed. After all of the interviews have been summarized, you will be asked to look at this to make sure that your ideas, thoughts, and/or feelings were correctly depicted. The audiotapes will be destroyed when the study is completed. The transcripts will not contain your personal identity. Any participation in this study will not affect the quality of future services provided by Arlington or Fairfax County.

At the first interview, the researcher will discuss the study purpose, ask questions to make sure that you meet the study criteria, review and discuss the consent form, and talk to you about yourself and your child and your experiences in early intervention. You will be sharing personal information about your life with your child, and how occupational therapy in early intervention affected the quality of your family's life. This interview will take 60-90 minutes. You will be asked for your address to mail the summary of the interview. If you decide to be in the study, you will be asked to sign this consent form after all of your questions have been answered. Participation in this interview is not related to any of the services or resources, including early intervention that you as a parent have sought out and used since your child was found to need services. Your decision to participate will in no way affect the services you are receiving or receive in the future.

A second interview may be done to clarify any thoughts or meanings that might not have been clear after the first interview. This interview will be over the telephone or at a location you choose and will be audiotaped.

The third contact will be by mail. In the mail you will receive a summary of the categories and themes from the interviews. You will be asked to look over the summary and add any comments to clarify meanings and make clear any misunderstandings. You will be asked to send back the summary with your comments in the envelope provided.

Risks and Discomforts:

This study was not proposed to cause any physical, financial, or mental risk. You may not derive any personal benefit from participating in this study. Development of questions for the interview will try to be open-ended, so that participants will not feel that it is necessary to discuss topics they may not feel comfortable in discussing related to their early intervention experience. Participation in the interviews will take some of your time and this may make scheduling difficult.

Initial _____

Page 3 of 4

Benefits:

This is not a medical study, and there are no medical benefits to being in this study. You may not derive any personal benefit from participating in this study. You may indirect benefit from participating in this study, in that you will be giving helpful information about your experiences with early intervention.

Costs:

There is no cost to be in this study. The interview will be scheduled at a time that will not interfere with your job or other commitments.

Alternatives:

This is not a treatment study. You can choose not to participate in this study.

Confidentiality:

We will not tell anyone the answers you give us; however, information from this study and information from the consent form signed by you may be looked at or copied for research or legal purposes by Virginia Commonwealth University. The investigator will treat your identity and information with professional standards of confidentiality. Your name, the name of your child, or the names of any persons discussed during the interview will not be used in the summary or reports written from this study. The audiotapes used will be destroyed upon completion of the study. The information from this study may be presented at meeting or in publications, such as journals. Your identity will not be revealed in those presentations.

If an Injury Happens:

Virginia Commonwealth University and the VCU Health System (also known as MCV Hospital) do not have a plan to give long-term care or money if you are injured because you are in this study.

If you are injured because of being in the study, tell the study staff right away. The study staff will arrange for someone to care for you if needed.

Bills for treatment may be sent to you or your insurance. Your insurance may or may not pay for taking care of injuries that happen because of being in this study.

Voluntary Participation and Withdrawal:

You do not have to participate in this study. If you choose to participate you may stop at any time without penalty. You may also choose not to answer any particular questions that are asked during the study. If you are currently receiving early intervention services, and you decide not to participate, your early intervention services will continue to be provided as before. In addition, any participation in this study will not affect the quality of future services provided by Arlington or Fairfax County.

Initial _____

Page 4 of 4

Questions:

In the future, you may have questions about your participation in this study. If you have questions, contact:

Student Researcher:

Juliet Copeland, OTR/L
104 W. Westmoreland Road
Falls Church, VA 22046
(703) 241-9791

Faculty Advisor:

Dianne Simons, PhD, OTR
Virginia Commonwealth University, Department of Occupational Therapy
(804) 828-2219

If you have any questions about your rights as a research participant, you may contact:

Office for Research Subjects Protection
Virginia Commonwealth University
800 East Leigh Street, Suite 111
P.O. Box 980568
Richmond, VA 23298
Telephone: (804) 828-0868

Consent:

I have been given the chance to read this consent form. I understand the information about this study. Questions I wanted to ask about study have been answered. My signature says that I am willing to participate in this study.

 Participant name printed

Participant signature

Date

 Witness Signature (**Required**)

Date

 Signature of person conducting informed consent

Date

 Investigator Signature (if different from above)

Date

APPENDIX L

Preliminary Participant Interview Feedback Form

- Were the questions appropriate for the topic of study? Any unnecessary or repetitive ones?
- Were there any questions that made you feel uncomfortable?
- Did any of the questions seem unclear, biased, or leading in any way?
- Did you feel comfortable answering all of the questions asked?
- Did you feel the length of the interview was a reasonable length?
- Were you able to express all of the information you wanted to share about your experiences with early intervention, occupational therapy and sensory diets?
- Did you have difficulty understanding the wording of any of the questions?
- Did you feel that the researcher was respectful at all times during the interview?
- Did you get time to talk about everything you felt was important?
- Please comment on the researchers interviewing style.
- Do you have any additional comments you would like to share regarding the researcher or the interview?

APPENDIX M

Loose Sorting Method of Grouping Similar Statements Together

Code	Definition	Participant Quote
Pat Specific sensory strategies used	Massage techniques, deep hugs, brushing firmly with towels, sensory play during mealtimes	The two most natural that come into mind for children who are very young would be – massage techniques. Um, I teach that to just about every family, even with older children. Um, massage, deep hugs, because that gives some deep proprioceptive input. And then, sometimes during bathing, um, certain things like brushing firmly with towels. Um, with some children, feeding, during feeding, that's a great time to do activities that involve touching the food, experimenting with the food, checking out scents of food, tastes.”
Types of strategies used	Provide strategies of deep pressure, deep proprioceptive input to help children stay organized, and also suggestions for de-sensitization using play	Most of the strategies that I've used here – that I've mentioned – I use to help, um, they provide deep pressure, deep proprioceptive input to help children stay organized. I also do some as kind of de-sensitization a little bit – that – by play, they can slowly work their way through, using almost a cognitive override or motivation. They can use their play to work through some sensations that maybe don't feel comfortable to them”
Reported results of sensory diets	deep pressure massage and swinging allowed more parent-child interaction, more eye contact	It allows families to – parents to interact with the child so that – in a way that they never have before. Because often times – their child is running around, or fleeing from one activity to the next, or having a hard time being contained in a hug. I've had many families who have been able to – um, actually have their child sit on their lap and read a book, after doing some of the sensory diet activities.
Educating parents	Educating parents to incorporate strategies into the daily routines of dressing, bathing, tooth-brushing, naptime, mealtime and play activities	Having parents re-look at what their child does on an everyday basis that we all do in terms of getting up, getting dressed, um, eating, cleaning, hygiene. And taking each of those and breaking them down and saying what components of these can we adapt to provide more sensory-um-sensory organizing feedback.
Nicki Sensory Diet Activities Used in the Past	beans, water deep pressure, massage with lotion, swinging, food play to increase intake, jumping off couch, spinning in office chair	we used to do work with beans and water and, um, deep pressure, and you know- firm - firm pressure, and um he used to wear Theratogs for some time. And, um those things really seemed to work to organize him. Um, at the park we often let him – he loves to do things like swinging – Pat had encouraged us to let him swing until he sort of – done, you know and then let him move on to the next thing
occupational therapist as a coordinator of services	Whole child, whole family view	She really seemed to be the one to be coordinating those and understanding those and understanding our kid.... So she was, I think helped our family in that way...really organizing, helping me organize and coordinate, um, different services... she really took a very whole child, whole family view.

Loose Sorting Method of Grouping Similar Statements Together (continued)

Code	Definition	Participant Quote
The model has informed everything she does with him	Present sensory diet strategies: Firm pressure, bump-bumps (jt. compressions), visual cues (boardmaker cards), predictable consistent routine, oral motor/ oral awakening activities	so those are some of the ways, day to day, sensory integration has helped us, but I think the model has informed everything that we do with him. I mean, we use a lot more visual cues, um, 'cause we know that that's a strength for him. Um, we use the firm pressure – that – that we do often – that's one of those things that like you can do anywhere at anytime – with a big squeeze, and some bump, bumps ... we call them bump bumps – joint pressure, whatever – Pat taught us how to do those Well, insofar as sensory integration relies on predictability and consistency – we certainly use a lot of that with our son. I mean, morning, noon, and night we program his life. And he really seems to respond to that
Felt her occupational therapist used a teaching or psycho-educational model	Teaching parent - trickles down to parent teaching caregivers - and then down to parent teaching child to self-regulate or ask for what he needs	Um, but she really showed us how to – I guess – what's the word I would use there – empower him" it educates the way that we – you know - informs the way that we talk to people who we rely on to take care of him." being able to identify opportunities for, um, sensory input in just regular things, and any old things. You know ... the tissue paper that... comes in ... a gift wrapping or something, that we immediately take that out and consider it as – "oh, this, you know, a toy, now" And so now we take that and store it and we think of an activity we can come up with – crinkling the paper, ripping the paper. As opposed to... five years ago, when I didn't know anything about this area – I would have just thrown the paper – its garbage.... So now those things aren't garbage any more – they're an opportunity for... an enriched sensory experience
Therapy was geared towards her as a mom	support, discipline tips, couples issues, community supports	A lot of therapy I think initially was geared towards me... There were lots of weeks that she came and J just sort of did his thing and she and I just talked about how he needed a mom who wasn't going to pity him, and who wasn't going to sort of enable a disability by doing everything for him, and... who was going to challenge him to be what ... he's certainly capable of being. And then... just couples issues about... how to handle between you and your spouse... – a child with differing needs and ... what that means to you and your marriage, and ... given that your child is ... an ego extension of you, and ... – all that psychotherapy stuff.

APPENDIX N

Excerpt from Initial Coding List

Person Interviewed	Code	Definition
Pat Nicki Frances Kay Amy Cindy Missy June	Sensory strategies: deep pressure/ proprioceptive (blue gray) (blue gray bold)	Sensory strategies that include deep pressure &/or proprioceptive input and help a child self-regulate or interact more with caregivers or peers.
Nicki Frances Cindy Betty Pat Missy	Etched into routine (violet) (violet bold)	Sensory diet as a “way of life”: the model has informed everything that we do with him.
Pat Kay Missy June	Family Centered Approach: family priorities (plum bold)	focusing on what the priorities are for that family and giving them strategies that can be incorporated into their lifestyle and whatever a normal day looks like for them
Amy Kay June Missy	Sensory diet: getting parents “on board”: go slow (plum bold)	Therapist comments on how she gets parents invested in a sensory diet by going slow and introducing only one or two strategies at a time
Pat Nicki Kay Cindy June	Parent teaching: awareness of sensory strategies (teal) (teal bold)	After OT teaching: parents more aware of helpful sensory strategies
Frances Betty Missy Kay Amy	Parenting strategies: problem solving (dark yellow) (dark yellow bold)	Occupational therapist teaching parent to problem solve how to address child’s sensory issues
Pat Amy Kay Missy	Sensory Diet: Rationale: regulation/organization (bright green bold)	Occupational therapists discuss reason for using sensory diet as helping child tune in to what’s important, tune out what’s not important, and help him deal comfortably with sensory intrusion

Excerpt from Initial Coding List (continued)

Person Interviewed	Code	Definition
Nicki Pat Kay Amy Cindy Missy June Betty	Sensory Diet Effects: organization/regulation /attention (aqua) (aqua bold)	Using the sensory diet strategies to help the child be more calm and organized

APPENDIX O

Emerging Themes

Research Question	Category	Codes
How do occupational therapists in early intervention define sensory diets?	Definitions	<ul style="list-style-type: none"> □ Daily family activities that include play or self-help that are used to help a child enhance processing of sensory information – do this so we can help children maintain organization, self-regulation, attention, focus. □ Parent: Incorporating things your occupational therapist has helped you identify as your child's needs into daily life □ Activities children do to give them the input they need – incorporate parents into coming up with strategies to do before an activity to get the response they want from the child. □ Prescriptively providing sensory input at regular intervals throughout the day to improve the child's ability to complete functional tasks, self-regulate and address issues of tactile defensiveness. □ Sensory experiences a child needs to optimize their ability to learn and function (I like this one!! Very concise). □ Activities that naturally occur in the home that are positive for the child and help him stay centered and calm.
	Rationale	<ul style="list-style-type: none"> □ To help children maintain organization, <u>self-regulation</u>, focus: □ Promotes improved interaction: □ Behavioral Changes □ Improved comfort with movement □ Increased body awareness □ Ocular changes □ Desensitization □ Effect on ADL's □ They allow the child to develop as normal as he can, to interact with his environment □ How do I decide what to use? <ul style="list-style-type: none"> ○ Trial and error ○ Culture ○ What's in the house ○ Gut □ Cater to the child's needs □ Sensory diet as part of a whole tx plan

Emerging Themes (continued)

Research Question	Category	Codes
	Use term sensory diet vs. sensory strategies	<ul style="list-style-type: none"> <input type="checkbox"/> With a language barrier <input type="checkbox"/> Tell parents about sensory based activities-activities that promote the child's sensory processing skills <input type="checkbox"/> Depends on a parent's educational level <input type="checkbox"/> Focus on strategies and activities, not terms <input type="checkbox"/> Say 'sensory experiences' <input type="checkbox"/> Connect term to Wilbarger <input type="checkbox"/> Emphasize what it's going to do for the child and help the parent-child relationship <input type="checkbox"/> Addressing behaviors that are difficult for the family
What strategies are occupational therapists typically using with families, and why?	Favorites	<ul style="list-style-type: none"> <input type="checkbox"/> Anything can be a sensory diet <input type="checkbox"/> Look at what a kid has in their house and what's typical in their routine <input type="checkbox"/> <u>Have deep pressure input</u> (Pat, Missy, June) <input type="checkbox"/> <u>Massage: ball massage, infant massage</u> <input type="checkbox"/> <u>Brushing briskly with towels</u> <input type="checkbox"/> <u>Bear/deep hugs</u> <input type="checkbox"/> Sensory play with feeding, chewies, properties of foods <input type="checkbox"/> <u>Heavy work activities: pillow sandwiches, resistive play</u> <input type="checkbox"/> Teaching the difference between heavy and light touch
	Deep Pressure Proprioceptive	<p>A lot of the favorites fall here as well, heavy work activities are also in the category</p> <ul style="list-style-type: none"> <input type="checkbox"/> <u>Massage: ball massage, infant massage</u> – helps with attention, bonding <input type="checkbox"/> <u>Hugs</u> <input type="checkbox"/> <u>Heavy work: pushing bike, cart, carrying backpack, groceries, laundry, resistive play</u> <input type="checkbox"/> Firm pressure: <u>pillow sandwiches</u> <input type="checkbox"/> <u>Wheelbarrow walking</u> <input type="checkbox"/> Weighted: vest, blanket, lap lizard, and swaddling <input type="checkbox"/> <u>Brisk towel rub</u> <input type="checkbox"/> Brushing: but need commitment, not a "good fit" in natural environment

Emerging Themes (continued)

Research Question	Category	Codes
What sensory strategies are families using on a daily basis?	Vestibular	Helps organize, but trickier <input type="checkbox"/> Bouncing on ball <input type="checkbox"/> Swinging <input type="checkbox"/> Trampoline <input type="checkbox"/> Pillow play
	Desensitization	<input type="checkbox"/> Using cognitive override with play <input type="checkbox"/> Just right sensory challenges <input type="checkbox"/> Hand squeezes and clapping
	Home	<input type="checkbox"/> <u>Decreasing environmental stimulation</u> : Turn off the TV, no TV before bed <input type="checkbox"/> <u>Pillow sandwiches</u> <input type="checkbox"/> <u>Decreasing visual clutter by putting toys away</u> <input type="checkbox"/> <u>Booster seat</u> <input type="checkbox"/> Hide out space, putting up a tent for quiet time <input type="checkbox"/> Incorporating strategies into routines
	Providing Therapeutic Items	<input type="checkbox"/> Try out in sessions, lend to try out <input type="checkbox"/> Tx balls easy to find at Target, Wal-mart <input type="checkbox"/> Helping parents find resources <input type="checkbox"/> Family is the one to decide if strategy (such as weighted vest) provides enough change to warrant it's use <input type="checkbox"/> Brushing: strangest strategy for the natural environment
	Child sensory-based behaviors	<input type="checkbox"/> <u>Interrupted sleep</u> <input type="checkbox"/> <u>Sensory seeking</u> : appear to be aggressive <input type="checkbox"/> Self- isolating behaviors <input type="checkbox"/> Overdependence on adults for stimulation <input type="checkbox"/> Difficulty engaging with peers <input type="checkbox"/> Very unhappy, angry <input type="checkbox"/> Poor body awareness, uncoordinated <input type="checkbox"/> <u>Finicky about textures</u> , environments, sensory avoidance <input type="checkbox"/> Spinning things, repetitive activities <input type="checkbox"/> Poor auditory processing – can't understand other kids, sensitivity to loud sounds <input type="checkbox"/> Decreased attention: <u>Can't sit still</u> , trouble in preschool <input type="checkbox"/> Issues not obvious to people outside the family <input type="checkbox"/> My kids don't act like other kids <input type="checkbox"/> Chicken or egg: did sensory cause poor engagement with toys, movement, or vice versa?

Emerging Themes (continued)

Research Question	Category	Codes
	Sensory processing affects adaptive function	<ul style="list-style-type: none"> <input type="checkbox"/> Parents see behaviors, such as I can't brush his teeth <input type="checkbox"/> She hates toothbrushing still <input type="checkbox"/> Potty training was very difficult – no awareness
	Strategies currently using	<ul style="list-style-type: none"> Parent amazed at how many strategies still using because they were so helpful <ul style="list-style-type: none"> <input type="checkbox"/> Outside at least once a day <input type="checkbox"/> Proprioceptive input is key <input type="checkbox"/> Firm pressure <input type="checkbox"/> Scheduling with visual prompts <input type="checkbox"/> Making sure he gets what he needs prophylactically <input type="checkbox"/> <u>Joint pressure.</u> <input type="checkbox"/> <u>Heavy work activities:</u> Carrying groceries/laundry basket <input type="checkbox"/> <u>Jumping off the couch</u> <input type="checkbox"/> <u>Pushing stroller/riding or pushing bike</u> <input type="checkbox"/> <u>Oral motor</u> <input type="checkbox"/> Desensitization <input type="checkbox"/> Community/preschool <input type="checkbox"/> At home: <ul style="list-style-type: none"> <input type="checkbox"/> <u>Obstacle courses</u> <input type="checkbox"/> 15 minute transition warning <input type="checkbox"/> Eyeball to eyeball for discussion <input type="checkbox"/> <u>Routine/predictability as a strategy</u>
	Strategies have changed over time	<ul style="list-style-type: none"> <input type="checkbox"/> Because of maturation and increased communication <input type="checkbox"/> Did sensory more when younger <input type="checkbox"/> Future concerns are that <ul style="list-style-type: none"> <input type="checkbox"/> He will require sports to meet his needs <input type="checkbox"/> Will need more OT help later <input type="checkbox"/> Would prefer her to have oral strategies, instead of proprioceptive – can't have a trampoline in her office <input type="checkbox"/> Some strategies no longer used <input type="checkbox"/> Some strategies unsuccessful
	Child directs own sensory diet	<ul style="list-style-type: none"> The ultimate goal! <input type="checkbox"/> 1st step: Helping child direct sensory input: <input type="checkbox"/> 2nd step: Child awareness of sensory processing issues <input type="checkbox"/> 3rd step: Child requests sensory input <input type="checkbox"/> 4th step: Child directs own sensory input

Emerging Themes (continued)

Research Question	Category	Codes
How did occupational therapy assist in the development of these strategies?	Being Family centered	<p>Relationship</p> <ul style="list-style-type: none"> <input type="checkbox"/> Occupational therapist encouraged parent <input type="checkbox"/> Therapist gets to know family, its needs and problem areas, through weekly communication <input type="checkbox"/> Go slow: <input type="checkbox"/> Became a “partnership”: problem solving together <input type="checkbox"/> Therapy geared toward training the caregiver <input type="checkbox"/> Begin with incorporating family strategies and move toward family problem solving own strategies <input type="checkbox"/> Knowledge of family resources determines pace of instruction <input type="checkbox"/> Being aware of cultural differences <p>Adapting the natural environment</p> <ul style="list-style-type: none"> <input type="checkbox"/> Therapist scans family environment for potential strategies or adaptations – see what’s around the house and come up with strategies from that. <input type="checkbox"/> Don’t take toys <input type="checkbox"/> Finding ways to put things in the environment that the child seeks on his own <input type="checkbox"/> Anything can be a sensory diet <p>Embed strategies into routines</p> <ul style="list-style-type: none"> <input type="checkbox"/> Therapists look at family’s day – where they go, what they do and what caregivers and focus on the biggest challenge areas <input type="checkbox"/> Re-look at what the child does daily for ADL’S and break these activities down to see what can be adapted to provide more sensory organizing feedback <input type="checkbox"/> Writing goals in tune with daily routines and occupations <p>Is it Sensory or is it Behavior?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Parents have to be able to see and identify what behaviors are unacceptable <input type="checkbox"/> Therapist helps parent identify unacceptable behaviors <input type="checkbox"/> Parents see the behaviors getting better, they don’t see it as their child’s sensory system getting better <input type="checkbox"/> Sensory seeking children appear to be aggressive

Emerging Themes (continued)

Research Question	Category	Codes
How do these sensory strategies fit into the family's everyday routines and occupations?	Therapist Training/Parent Education	<ul style="list-style-type: none"> □ Courses occupational therapists took to assist them in the development of sensory strategies □ Sensory Processing □ Sensory strategies to ameliorate behaviors □ Occupational therapist helped parent to help child □ Occupational therapist provided resources to parents □ Parenting Strategies: behaviors □ Teaching problem solving □ Parents expanding on therapist strategies
	Parent Education	<ul style="list-style-type: none"> □ Encompasses activities that can be carried out within the framework of a family's daily activities □ Therapist requires family participation in tx □ Therapist writes goals that go along with family routines and occupations □ Teaching all of the caregivers/participants in child's natural environment □ Look at their day – where they go, what they do, with what caregivers and focus on the biggest challenge areas □ Re-look at what the child does daily in terms of ADL's and break activities down and see what can be adapted to provide more sensory organizing feedback □ Family has to be willing to have some flexibility in changing the way they are currently operating □ Helping mommy carry groceries, pushing the stroller or grocery cart, carry the laundry basket □ Home: □ Childcare □ Preschool □ Community places/programs □ Library/storytime □ Playgroup □ Decreasing environmental stimulation □ What's in the home

Emerging Themes (continued)

Research Question	Category	Codes
	Etched into Routine	<p>The model has informed everything we do with him, gradually became a “way of life”</p> <ul style="list-style-type: none"> □ Strategies are incorporated into daily routines □ Incorporate child into daily chores that feed his sensory needs □ We’ve integrated them into our daily practice – don’t even know that we’re doing them □ Sensory strategies useful for all moms □ Sensory strategies are easy to use, natural and fun □ Allowing the otherwise forbidden with the child with SPD

APPENDIX P

Post It Method Themes: Therapists

Emerging Themes	Supporting Quotes
All therapists recommend strategies of deep pressure, proprioceptive or heavy work input	<ul style="list-style-type: none"> <input type="checkbox"/> Deep pressure (P,K,M,J)* <input type="checkbox"/> Heavy work (A) <input type="checkbox"/> It is organizing (P, J) <input type="checkbox"/> Helps everybody (M, J)
Therapists use what's in the (client/family's) environment/ Use their stuff	<ul style="list-style-type: none"> <input type="checkbox"/> Settings: home, child care/day care, preschool, community settings, playgroups (P,J) <input type="checkbox"/> (P) Intervention takes place in environments natural for the child, Need creativity to pair sensory organizing activities to home, Helping parents creatively look at everything they do and how to add a sensory component to that task <ul style="list-style-type: none"> <input type="checkbox"/> I don't take toys, looking at what's available in homes <input type="checkbox"/> (M) I try every other avenue (than therapeutic equipment) so the kid doesn't look different, I look around what's in the house and come up with strategies from that <input type="checkbox"/> (K) Use what's in the environment/go first to what's there, find ways to put things in the environment that he can seek on his own <input type="checkbox"/> (J) A comfortable ability to deal with the environment is critical to learning it, Take what's in the household and use their stuff
Family centered = parent/therapist "partnership" with parent "on board" and guiding direction and pace of treatment	<ul style="list-style-type: none"> <input type="checkbox"/> (P) Goals based on challenges and needs a family has <input type="checkbox"/> (A) Get parents "on board," Incorporate family into daily routines, Getting to know family – where they want changes, where the issue is, most difficult part of their day <input type="checkbox"/> (M) Problem solving with parents – they have to buy in, Direct tx to fit the family's lifestyle – what they're willing to do, Need her participation, "partnership" of ongoing assessment of what's working, not working for parent, Role of consultant/educator: observe and listen to what parents are saying <input type="checkbox"/> (K) Family priorities guide tx – where it begins, where it goes, If we try it and it's not making a significant impact – not worth it <input type="checkbox"/> (J) Emphasize more – what it's gonna do and how it's gonna help the parent child relationship, Parent has to be "on board" or it doesn't work
Therapist gauges pace of treatment from scan of family context	<ul style="list-style-type: none"> <input type="checkbox"/> (A) I check in every week – they give me weekly feedback on strategies <input type="checkbox"/> (M) I went slowly with mom, One activity to start – baby steps, one activity/week, Start with biggest challenge areas 1st and start there <input type="checkbox"/> (K) One or two strategies to start <input type="checkbox"/> (J) Leave one idea and see how it goes – with these babies – it's one step at a time, Use gut observation of what family resources are – emotional and energy resources (# children, food, heating, clothes, etc.) and the more concerns, the slower I go

Post It Method Themes: Therapists (continued)

Emerging Themes	Supporting Quotes
Use child's behaviors as a starting point with educating parents	<ul style="list-style-type: none"> □ (A) Build on what the child likes to do already, Use child's behavior to show parents what input child needs □ (M) It's always behavior that brings me in – it's never a sensory thing, What is child seeking/avoiding – go there 1st □ (K) I point out to parents – the things I already see the child doing to compensate, I can tell it's working by the behavior changes that I see □ (J) Look at the difficult behaviors for the family, They're looking at behaviors – so that's what I'm looking at, too, Giving parents observations – what to look for, Want them to feel positive and take charge and handle it and not be overwhelmed
Sensory diet effects reported	<ul style="list-style-type: none"> □ Increased engagement <ul style="list-style-type: none"> (P) Family interacting with child in a way they never have before (A) Increased interaction with siblings, Sitting longer for family meals (M) Increased engagement with children at preschool (K) Increased ability to play with peers/siblings (J) Increased engagement □ Increased self-regulation for: <ul style="list-style-type: none"> □ Attention (K) □ Sleep (J) □ Regulation/Calm/Coping (K, A, J)

* **Key:** A: Amy
J: June
K: Kay
M: Missy
P: Pat

Post It Method Themes: Parents

Emerging Themes	Supporting Quotes
Understanding and acceptance	<ul style="list-style-type: none"> □ (N)** EI: springboard for us understanding the importance of understanding our son through more than what you see from the outside, He is much more organized and we are much more aware of those things that make him disorganized, being able to understand that piece (what his sensory needs are) is the gift that Pat gave us, Pat helped me understand that he has a CNS that processes sensory information differently than other children □ (F) EI taught me not to apologize and explain – to accept her for who she is and not excuse her, She’s going to continue to need her own space □ (C) I was using the same rules with him as his twin sister and I came to realize through occupational therapy – he can’t control himself like she can – we have to satisfy his needs 1st, then put rules in place □ (B) Her final words to me were to keep up with the information regarding their age levels as they changed – so you can change with them, (Discussing her rationale for strategies she uses) I remember most her comment to me – the concept of grounding – when he’s using his muscles a lot there is a release of tension – it almost causes a pause – where he can exhale and have a chance to slow down for a minute, The same with big hugs – it creates a pause
Supporting Mom	<ul style="list-style-type: none"> □ (N) Treatment geared towards mom, occupational therapist became part of our family, Supporting me in my mothering and advocating for him, □ (F) I think it’s (occupational therapy) made family life possible, And so she’s the one who suggested day care – so, and for me it was a godsend, because I didn’t realize how unhappy I was at home full time □ (C) I definitely received parenting strategies- (in the form of) – pat on the back, you’re doing the right thing, hang in there, Helped with finding the right preschool for him – I think they were able to see Eric in 6 months easier than I was able to see Eric in 6 months □ (B) They were good things for all moms, June had a lot of suggestions for handling a big trip at the airport and in transit
Sensory Diet Effects	<ul style="list-style-type: none"> □ (N) He’s more regulated, more organized with increased attention, increased impulse regulation, We use firm pressure often – brings him back a little and organizes him □ (F) Occupational therapy made family life possible – now able to take her out, By the end of the year – able to sit for 10 minutes at circle time □ (C) He is a different child now □ (B) He’s calmer – he sat for a picture and for 15 minutes at a bird show, It makes a difference in his behavior – he’s calmer, Better able to listen to what I said, With eye to eye discussion of expectations before an event – his behavior is better

Post It Method Themes: Parents (continued)

Emerging Themes	Supporting Quotes
Promoting problem solving	<ul style="list-style-type: none"> <li data-bbox="456 464 1390 1018"> <p>□ Occupational therapist teaching changed our thinking</p> <p>(N) It's gonna take work to organize and understand his world – it's not gonna come naturally, Pat helped us find ways to meet his sensory needs without SI equipment, Pat helped us with limit-setting for a child with sensory processing disorder, Identify opportunities for sensory input in different media, Buy totally different toys now – puzzles and manipulatives, I became much more alerted to things like that - the more I was trained to think that way by Pat,</p> <p>(F) I put her in the class that did the most sensory stuff, Her day care has been very accommodating – incorporated sensory for all the kids, do sensory before circle time</p> <p>(C) Letting him do things that we probably wouldn't have let the other kids do – like the jumping and not forcing foods on him,</p> <p>(B) One of the things she helped me with was the importance of routine – a consistent pattern of things – so he knows what's coming next, Things that June was talking about to a great extent – those haven't changed – those strategies are like a foundation, I'm using the same stuff with her (other child) all the time – and I find it's equally as effective to get her to settle down. It's like that idea of teaching a man to fish rather than giving him something to eat</p> <li data-bbox="456 1024 1390 1354"> <p>□ Teaching me how to help him</p> <p>(N) She showed us how to empower him – challenge him to be what he was capable of being, Informs the way we talk to people who we rely on to take care of him</p> <p>(F) Goal was to teach me to interact with my child and help her and it worked, occupational therapist was teaching me how to do the things (with modeling) and how to watch for the signs</p> <p>(C) I was able to easier verbalize his concerns, issues and needs to caregivers</p> <p>(B) June showed me ways I could do things differently by me guiding the hugs and physical activities – I helped his environment, Therapy required me doing things specifically in a certain way to help him</p> <li data-bbox="456 1360 1390 1696"> <p>□ Expanding on therapist strategies</p> <p>(N) Added to boardmaker card use – use feeling cards plus, red, yellow, green behavior cards</p> <p>(F) I bought her this heavy steel bike because I figured – the harder she had to work – the more proprioceptive input she would get, Every morning she has to give me a hug, Finger painting in the bathtub with friends</p> <p>(C) We expanded with jumping on the couch – she definitely didn't advocate that – and jumping off onto cushions, We're doing different things now because he has matured, Then I think we're going to get to the point where he plateaus and I'm gonna need some help again</p> <p>(B) His routines have changed</p>

Post It Method Themes: Parents (continued)

Emerging Themes	Supporting Quotes
Sensory diet as a “way of life”	<ul style="list-style-type: none"> □ (N) The model has informed every thing we do with him – we use it more just in our daily lives, Used to do sensory before an event – but gradually became a “way of life” – incorporated it, Don’t rely on sensory input as much as we used to – used to do sensory more when younger, <i>SI relies on predictability and consistency morning noon and night we program our son</i> □ (F) Sensory diet is going to be totally a “way of life” □ (C) I think we’ve integrated them into our daily practice – don’t even think of them as tx anymore – it’s just a part of our normal practice, it’s become a family routine – the kids love to jump on the furniture and play on the exercise ball and we’re all outside together, Make sure those sensory needs are met throughout the day – he’s had the opportunity to jump and bounce, cuddle, play outside, in the sandbox, on the swing, I feel like we’re doing fine on our own now – we’ve got a lot of strategies – we’ve incorporated a lot of things into our normal routine and into our home □ (B) I don’t even notice it – I didn’t know I was doing it (until she looked back at her notes from tx and saw where it started), what’s interesting is how they became a part of the routine without even trying to make it so because they were so helpful
Strategies - used	<ul style="list-style-type: none"> □ (N) Use boardmaker cards for schedule – he really responds to that, Environmental strategies – playground equipment, taking batteries out of toys, Use firm pressure often – can do anywhere anytime – seems to help organize him, big squeeze/bump bumps (joint pressure), Do a lot of things that are pushing, pulling, grabbing and reaching, Incorporate him in chores – helping us put away groceries, push the laundry basket, Oral awakening activities help □ (F) Occupational therapist taught us all our strategies – head banging – pat and squish – jumping on furniture – trampoline – climbing walls – trapeze bar, Use strategies mostly in the PM to come down – trampoline, trapeze bar – we jump and swing, Proprioceptive input seems to be the key for her, We try to give her gross motor movement every day, A lot of trial and error to develop the strategies that fit, <i>She needs a structured day – we start the day by telling her what we are doing that day and in what order – talk about what’s coming next</i> □ (C) Has a cuddly, make sure he has the foods he likes, laying on leather cubes to get tummy pressure, rolling on the ball, Past strategies: deep pressure massage, joint compression, weighted vest, different textures, sensory stimulating foods, bounce on ball, wheelbarrow walking, At preschool – teachers squeeze and push down on his shoulders, Making sure he gets plenty of physical activity – we let him jump on the furniture □ (B) They’re just fun things you come up with doing on a daily basis, Every morning is out – we do things – we try to run off steam and get out and do physical things, Pushing the lawnmower – June said that was a good thing for him – grounding him – keeping those muscles busy so that he could have a chance to regroup and focus later on, We play hide and seek – a very physical activity in our house – almost everyday there’s a portion of the day where we’re on the sofa and hiding behind the cushions, We do a lot of tickling – he loves to be upside down, We build forts in the living room with cushions and blankets, Eye to eye and talking to him – often accompanied by hugs – to settle him down – I can get his attention – I can get him to listen to me, That transition time became very helpful- 15-10-5 minute warning – June had told me that was a way to help him to be able to be ready to do and focus on the next thing

Post It Method Themes: Parents (continued)

Emerging Themes	Supporting Quotes
Child directed strategies	<ul style="list-style-type: none"> □ (N) Pat taught us to make sure he gets what he needs proactively everyday so that he would learn to organize himself and begin requesting what he needs, Mommy I need input in my mouth, He would guide us to what he needed on a particular day or time starting to verbalize basic needs now □ (F) If I notice she's having a hard time coming down – I will ask her what she needs and she will tell me – I need pat, squish, bear hugs, I have found her giving herself 'pat', When she asks we do pat, squish, bear hugs – she's pretty much able to tell me if she needs them, I would like to see her start to totally regulate it and give herself input – right now – she doesn't always know what she needs – ¾ times she needs prompting, When she gets overwhelmed – she goes upstairs to her room □ (C) So it's getting a little bit easier – he's learning more self-regulation techniques, I don't have a prescription that I use during the day to meet his sensory needs – when I feel like he needs it – is when we do it, He will go and do the things himself and just ask for my help – he'll grab my hand and take me to the living room and say 'dance', He'll tell me if he wants to swing, He'll say – mommy I need pretzels, And go and get it – get things on his own, And then over time – he started to figure out things that he liked and didn't like □ (B) He's the one asking me to do the stuff – can we play chase? Can you put me upside down? – or he'll say – let's build a fort or a tunnel

****Key:**
 B: Betty
 C: Cindy
 F: Frances
 N: Nicky

APPENDIX Q

Evolution of Themes during the Analysis Process: Preliminary Findings

Preliminary Clustering	Research Question Themes	Post It Method	Preliminary Inferences
<ul style="list-style-type: none"> • Family Centered Therapy 	<p>How did occupational therapy assist in the development of these strategies?</p> <ul style="list-style-type: none"> • Being Family Centered • Is it Sensory or is it Behavior? • Therapist Training • Parent Education 	<p>Therapists</p> <ul style="list-style-type: none"> • Use what’s in the environment/ Use their stuff • Family centered = parent/therapist “partnership” with parent “on board” and guiding direction and pace of treatment • Therapist gauges pace of treatment from scan of family context • Use child’s behaviors as a starting point with educating parents 	<p>Therapists</p> <ol style="list-style-type: none"> 1. Being family centered involves <ol style="list-style-type: none"> a. Establishing a “partnership” type of relationship with the parent to get the parent “on board” and to provide a supportive context for collaboration on how to best help the child toward optimal functioning within the family and the extended community b. Scanning the family environment and resources and using this information for the pace of treatment and for development of potential strategies c. Use the child’s behaviors as a starting point for educating parents
<ul style="list-style-type: none"> • Favorite sensory strategies • Sensory strategies not successful or not used because not useful 	<p>What strategies are occupational therapists typically using with families, and why?</p> <ul style="list-style-type: none"> • Therapists have favorites, including <ul style="list-style-type: none"> ○ Deep Pressure ○ Proprioceptive ○ Vestibular ○ Oral Motor ○ Desensitization ○ Home Modifications 	<ul style="list-style-type: none"> • All therapists use deep pressure, proprioceptive or heavy work input 	<ol style="list-style-type: none"> d. Use a lot of deep pressure and heavy work strategies because they fit into the family’s routines, are organizing to the child, and work for children with varying issues 2. Sensory diets help children to be more engaged with their families and with other children and have improved their regulation and focus for participation in family routines and self-help activities.

Evolution of Themes during the Analysis Process: Preliminary Findings (continued)

Preliminary Clustering	Research Question Themes	Post It Method Themes	Preliminary Inferences
<ul style="list-style-type: none"> Favorite sensory strategies Sensory diet effects reported 	<p>What sensory strategies are families using on a daily basis?</p> <ul style="list-style-type: none"> To Address Child’s Sensory Based Behaviors Sensory Processing Affects Adaptive Function Current Strategies Used Strategies Have Changed Over Time Child Learning to Direct Own Sensory Diet 	<ul style="list-style-type: none"> Sensory Diet Effects <ul style="list-style-type: none"> More regulated, organized Increased attention, impulse regulation Calmer 	<ol style="list-style-type: none"> Sensory strategies that were a “good fit” for the family became a “way of life” Child needs physical activity every day
<ul style="list-style-type: none"> Sensory strategies not successful or not used because not useful 	<p>How do these sensory strategies fit into the family’s everyday routines and occupations?</p> <p>How, Settings Etched into Routine</p>	<p>Parents</p> <ul style="list-style-type: none"> Understanding and acceptance Promoting problem solving Supporting mom Sensory diet as a “way of life” Current Strategies Child directed strategies Effects 	<p>Parents</p> <ol style="list-style-type: none"> Occupational therapist helped parents understand how their child processes sensory information differently and this understanding led to their acceptance of their child. Occupational therapist changed parent thinking and this led to: <ol style="list-style-type: none"> Changing their interaction with their child Changing his environment Advocating for their child Being able to generalize those ideas to new situations Supporting the parent helped support the child The ultimate goal is for the child to give himself input to regulate himself An effect of occupational therapy is that it made family life possible
<ul style="list-style-type: none"> Sensory diet definition 	<p>How do occupational therapists in early intervention define sensory diets?</p> <ul style="list-style-type: none"> Definitions, Rationale Terminology with parents: Sensory Diet vs. Sensory Strategies 		

Evolution of Themes during the Analysis Process: Progression of the Sensory Diet “Way of Life” Model

Initial Model How does a sensory diet become a “way of life”?	Interim Model How does a sensory diet become a “way of life”?	Final Model How does a sensory diet become a “way of life”?
	<p><i>Themes that Emerged from Therapists’ Perspectives</i> Sensory diets are used by therapists because they help a child with sensory processing difficulties get organized, self-regulate and focus on the skills needed for typical development</p>	<p><i>Themes that Emerged from Therapists’ Perspectives</i> Sensory diets are used by therapists because they help a child with sensory processing difficulties get organized, self-regulate and focus on the skills needed to promote development and socialization</p>
<p>Therapist scans the family environment and resources (physical, social and temporal) and uses this information to determine</p> <ul style="list-style-type: none"> • the pace of treatment • appropriate strategies based on family need and challenges 	<p>Once a therapist has identified that a child has sensory needs that was addressed with a sensory diet, the therapist scans the family environment to assess all of its naturally occurring resources (physical, social, cultural, and temporal) and uses this information to determine</p> <ul style="list-style-type: none"> • gradually introduce sensory diet strategies that will be a good “fit” for the child and the family • recommend appropriate strategies based on <ul style="list-style-type: none"> ○ what is available in the environment ○ family priorities ○ how it will enhance the parent child-relationship • whether or not to use the term ‘sensory diet’ or alternative language, such as <ul style="list-style-type: none"> ○ labeling and describing the specific sensation the child is seeking with their behavior ○ focusing on strategies and activities that will help improve the child’s difficult behaviors 	<p>Once a therapist has identified that a child has sensory needs that were addressed with a sensory diet, the therapist studies the family environment to identify all of its naturally occurring resources (physical, social, cultural, and temporal) and uses this information to</p> <ul style="list-style-type: none"> • gradually introduce sensory diet strategies that will be a good “fit” for the child and the family • recommend appropriate strategies based on <ul style="list-style-type: none"> ○ family goals and priorities ○ the needs of the child ○ what is available in the environment ○ how it will enhance the parent child-relationship as well as relationships with peers and other caregivers • whether or not to use the term ‘sensory diet’ or alternative language, such as <ul style="list-style-type: none"> ○ labeling and describing the specific sensation the child is seeking or avoiding with their behavior ○ focusing on strategies and activities that will help improve the child’s difficult behaviors

Evolution of Themes during the Analysis Process: Progression of the Sensory Diet “Way of Life” Model (continued)

<p>Initial Model</p> <p>How does a sensory diet become a “way of life”?</p>	<p>Interim Model</p> <p>How does a sensory diet become a “way of life”?</p>	<p>Final Model</p> <p>How does a sensory diet become a “way of life”?</p>
<p>Therapist establishes a “partnership” with the parent/family by</p> <ul style="list-style-type: none"> • Getting the parent “on board” <ul style="list-style-type: none"> ○ to provide a supportive context for collaboration ○ to best help the child toward optimal functioning within the family and the extended community • Using the child’s behaviors as a starting point for educating parents <p>Supporting the parent helps support the child</p>	<p><i>Themes that Emerged from Both Therapists’ and Parents’ Perspectives</i></p> <p>By focusing on family priorities, the therapist establishes a “partnership” with the parent/family by</p> <ul style="list-style-type: none"> • Getting the parent philosophically “on board” to provide a supportive context for collaboration on the child’s sensory processing issues • Using the child’s behaviors as a starting point for informing parents of the impact of sensory processing issues on function by <ul style="list-style-type: none"> ○ Identifying which of the child’s behaviors are difficult for the family ○ Showing parents what input the child is seeking and avoiding • Providing information, demonstration, role modeling and support to the parent so that they can in turn support the child. 	<p><i>Themes that Emerged from Both Therapists’ and Parents’ Perspectives</i></p> <p>By focusing on family priorities, the therapist establishes a “partnership” with the parent/family by</p> <ul style="list-style-type: none"> • Using the child’s behaviors as a starting point for informing parents of the impact of sensory processing issues on function by <ul style="list-style-type: none"> ○ Identifying which of the child’s behaviors are difficult for the family ○ Showing parents what input the child is seeking and avoiding • Providing information, demonstration, role modeling and support to the parent so that they can in turn support the child. • Getting the parent philosophically “on board” to provide a supportive context for collaboration on the child’s sensory processing issues.
<p>Therapists use a lot of deep pressure and heavy work strategies because</p> <ul style="list-style-type: none"> • They fit into the family’s routine • Are organizing to the child • They work across the board: for children with a variety of issues 	<p>Deep pressure and heavy work strategies are most often used by therapists in their sensory diet recommendations and parents continue to use them after early intervention services were discontinued because they</p> <ul style="list-style-type: none"> • Fit easily into many of the family’s routines (towel rubs, unloading groceries) • Are organizing to the child • Work across the board: for children with a variety of issues • The child continues to request them • Parents feel they help the child 	<p>Deep pressure and heavy work strategies are most often used by therapists in their sensory diet recommendations and parents continue to use them after early intervention services were discontinued because they</p> <ul style="list-style-type: none"> • Fit easily into many of the family’s routines (towel rubs, unloading groceries) • Are organizing to the child • Work across the board: for children with a variety of issues • The child continues to request them • Parents feel they help the child

Evolution of Themes during the Analysis Process: Progression of the Sensory Diet “Way of Life” Model (continued)

Initial Model How does a sensory diet become a “way of life”?	Interim Model How does a sensory diet become a “way of life”?	Final Model How does a sensory diet become a “way of life”?
<p>Occupational therapist helped parents understand how their child processes sensory information differently</p> <p>Occupational therapist changed parent thinking and this led to the following progression:</p> <ul style="list-style-type: none"> • Greater acceptance of their child. • A change in their interaction with their child • Making changes in his home environment <ul style="list-style-type: none"> ○ Child needs physical activity every day • Being able to generalize those ideas to new situations • Advocating for their child outside the home <p>The ultimate goal is for the child to give himself input to regulate himself and he is beginning to do that</p>	<p><i>Themes that Emerged from Parents’ Perspectives</i> Through parent consultation, information about the child’s unique sensory processing issues and how sensory diet strategies might help was transferred to parents. This information changed parent thinking and led to the following progression:</p> <p>Parents:</p> <ul style="list-style-type: none"> • Gain an understanding of how their child processes sensory information differently • Develop greater acceptance of their child. • Make changes in the home environment <ul style="list-style-type: none"> ○ Setting routines, scheduling transitions ○ Adding equipment ○ Child needs physical activity every day ○ Seeing opportunities for sensory input in everyday objects, furniture, and daily activities • Generalize those ideas to new situations • Advocate for their child outside the home in ever enlarging environments • View the ultimate goal to be for the child to recognize his/her own sensory needs and seek to get them met for their own self-regulation 	<p><i>Themes that Emerged from Parents’ Perspectives</i> Through parent consultation, information about the child’s unique sensory processing issues and how sensory diet strategies might help was transferred to parents. This information changed parent thinking and led to the following progression:</p> <p>Parents:</p> <ul style="list-style-type: none"> • Gain an understanding of how their child processes sensory information differently • Develop greater acceptance of their child. • Make changes in the home environment <ul style="list-style-type: none"> ○ Setting routines, scheduling transitions ○ Adding equipment ○ Child needs physical activity every day ○ Seeing opportunities for sensory input in everyday objects, furniture, and daily activities • Generalize those ideas to new situations • Advocate for their child outside the home in ever enlarging environments • View the ultimate goal to be for the child to recognize his/her own sensory needs and seek to get them met for their own self-regulation

Evolution of Themes during the Analysis Process: Progression of the Sensory Diet “Way of Life” Model (continued)

Initial Model How does a sensory diet become a “way of life”?	Interim Model How does a sensory diet become a “way of life”?	Final Model How does a sensory diet become a “way of life”?
<p>Sensory diets are effective in</p> <ul style="list-style-type: none"> • Helping children be more engaged with their family and with other children outside the home. • Helping children improve their regulation and focus for participation in family routines and self-help activities <p>An effect of occupational therapy is that it made family life possible</p>	<p>The use of sensory diets in occupational therapy early intervention services make “family life possible” because they help children with sensory needs</p> <ul style="list-style-type: none"> • Improve their regulation and focus for participation in family routines and self-help activities • Be more engaged with their family and with others within and outside the home. 	<p>The use of sensory diets in occupational therapy early intervention services make “family life possible” because they help children with sensory needs</p> <ul style="list-style-type: none"> • Improve their regulation and focus for participation in family routines and self-help activities • Be more engaged with their family and with others within and outside the home.
<p>Sensory strategies that were a “good fit” for them become a “way of life.”</p>	<p>Once the family sees the positive changes that incorporating a sensory diet has on their child with sensory needs, sensory strategies that were a “good fit” for them become a “way of life.”</p>	<p>Once the family sees the positive changes that come from incorporating a sensory diet into their child’s day, sensory strategies that were a “good fit” for them become a “way of life.”</p>

APPENDIX R

Sensory Diet “Way of Life” Model Following Member Checking

How does a sensory diet become a “way of life”?

Themes that Emerged from Therapists’ Perspectives

1. Sensory diets are used by therapists because they help a child with sensory processing difficulties get organized, self-regulate and focus on the skills needed to promote development and socialization
2. Once a therapist has identified that a child has sensory needs that were addressed with a sensory diet, the therapist studies the family environment to identify all of its naturally occurring resources (physical, social, cultural, and temporal) and uses this information to
 - a. gradually introduce sensory diet strategies that will be a good “fit” for the child and the family
 - b. recommend appropriate strategies based on
 - i. family goals and priorities
 - ii. the needs of the child
 - iii. what is available in the environment
 - iv. how it will enhance the parent child-relationship as well as relationships with peers and other caregivers
 - c. whether or not to use the term ‘sensory diet’ or alternative language, such as
 - i. labeling and describing the specific sensation the child is seeking or avoiding with their behavior
 - ii. focusing on strategies and activities that will help improve the child’s difficult behaviors

Themes that Emerged from Both Therapists’ and Parents’ Perspectives

3. By focusing on family priorities, the therapist establishes a “partnership” with the parent/family by
 - a. Using the child’s behaviors as a starting point for informing parents of the impact of sensory processing issues on function by
 - i. Identifying which of the child’s behaviors are difficult for the family
 - ii. Showing parents what input the child is seeking and avoiding

- b. Providing information, demonstration, role modeling and support to the parent so that they can in turn support the child.
 - c. Getting the parent philosophically “on board” to provide a supportive context for collaboration on the child’s sensory processing issues
4. Deep pressure and heavy work strategies are most often used by therapists in their sensory diet recommendations and parents continue to use them after early intervention services were discontinued because they
- a. Fit easily into many of the family’s routines (towel rubs, unloading groceries)
 - b. Are organizing to the child
 - c. Work across the board: for children with a variety of issues
 - d. The child continues to request them
 - e. Parents feel they help the child

Themes that Emerged from Parents’ Perspectives

5. Through parent consultation, information about the child’s unique sensory processing issues and how sensory diet strategies might help was transferred to parents. This information changed parent thinking and led to the following progression:
- Parents:
- a. Gain an understanding of their child’s unique way of processing sensory information
 - b. Develop greater acceptance of their child.
 - c. Make changes in the home environment
 - i. Setting routines, scheduling transitions
 - ii. Adding equipment
 - iii. Child needs physical activity every day
 - iv. Seeing opportunities for sensory input in everyday objects, furniture, and daily activities
 - d. Generalize those ideas to new situations
 - e. Advocate for their child outside the home in ever enlarging environments
 - f. View the ultimate goal to be for the child to recognize his/her own sensory needs and seek to get them met for their own self-regulation
6. The use of sensory diets in occupational therapy early intervention services make “family life possible” because they help children with sensory needs
- a. Improve their regulation and focus for participation in family routines and self-help activities
 - b. Be more engaged with their family and with others within and outside the home.
7. Once the family sees the positive changes that come from incorporating a sensory diet into their child’s day, sensory strategies that were a “good fit” for them become a “way of life.”

VITA

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Juliet is currently a graduate student at Virginia Commonwealth University. She graduated from the Edmund Burke Preparatory School in Washington, D.C. in 1981. She received her undergraduate degree in Psychology from New York University in New York, New York in 1986. She received a second undergraduate degree in Occupational Therapy from the State University of New York Health Sciences Center at Brooklyn in 1993.

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