

THE EFFECTS OF SENSORY ABNORMALITIES AND MALADAPTIVE
BEHAVIORS IN YOUNG CHILDREN WITH DISABILITIES ON
PARENT PARTICIPATION: A CORRELATION STUDY

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DEDICATION

This project is dedicated to my husband John, who agreed that this was “my time” and began systematically removing all obstacles to achieving my dream as soon as I was accepted at TWU. Thanks to my children who were a constant source of support: Matthew, my personal I.T. whiz; Luke, who makes me laugh at my own mistakes; and Nicolau, who provides hugs whenever needed. This project, my education, who I am today--none of it could have happened without the grounding love, encouragement and prayers of my parents, David and Lorraine Salto. They carry forth a legacy of faith, hard work, and dedication that has paid off in many versions of our family’s American Dream.

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ABSTRACT

ELAINA J. DALOMBA

THE EFFECTS OF SENSORY PROCESSING AND BEHAVIOR OF YOUNG CHILDREN ON PARENT PARTICIPATION: A CORRELATION STUDY

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The World Health Organization (WHO) defines participation as central to health. Occupational therapy views participation as both the means and end to health (AOTA, 2013). Family members are interdependent and their abilities to participate affect one another (Sameroff & Fiese, 2000). Therapists assess each family member's ability to participate when they intervene in a child's life (AOTA, 2008).

Children with various developmental delays demonstrate sensory abnormalities and maladaptive behaviors that cause parental stress (Baker, Blacher, Crnic & Edelbrock, 2002; Schaaf et al., 2011; Tomcheck & Dunn, 2007). Occupational therapy holds that maladaptive behaviors result from sensory processing abnormalities (Ayres, 1971; Dunn, 1997). Some literature supports these theories (Ashburner, Ziviana & Rodger, 2008; Lane, Baker & Angley, 2010). Other literature finds no relationship between sensory abnormalities and behavior (Hoehn, & Baumeister, 1994; Rogers and Ozonoff, 2005).

This dissertation explored the effects of abnormal sensory processing and maladaptive behaviors of young children with disabilities on their parent's ability to participate. It further explored the relationship between abnormal sensory processing and maladaptive behavior. These relationships were explored through correlation and

regression analyses with three tools: the Life Participation For Parents (LPP), The Infant Toddler Sensory Profile (ITSP), and the Child Behavior Checklist 1.5-5 (CBCL) on parent reports on 43 children.

Correlations between LPP and ITSP constructs showed no significant relationships. Correlations between LPP and CBCL 1.5-5 constructs revealed weak inverse relationships between Anxious/Depressed, Sleep Problems, Aggressive Behaviors and parent participation. Correlations between ITSP and CBCL 1.5-5 constructs showed weak inverse relationships between Low Registration and Anxious/Depressed Behavior and moderate inverse relationships between Low Registration and Withdrawn, Attention Problems, and Aggressive Behavior. Sensation Seeking showed weak inverse relationships with Emotionally Reactive, and a moderate inverse relationship with Attention Problems. Sensory Sensitivity had weak inverse relationships with Sleep and Avoiding, and moderate inverse relationships with Emotionally Reactive, Anxious/Depressed, Somatic, and Aggressive Behavior. Sensation Avoiding showed moderate inverse relationships with Emotionally Reactive, Anxious/Depressed, Somatic and Withdrawn between LPP and CBCL 1.5-5 constructs. Predictive relationships between Low Registration and Sensory Sensitivity characteristics and Internalizing Behaviors only were found.

Maladaptive behaviors were weakly related to lower parent participation however there was no predictive nature to these relationships in this sample of children.

Relationships between behavior and sensory processing constructs are stronger and some

predictive relationships were found. This supports theories that suggest that behavior is related to sensory processing experiences.

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CHAPTER I

INTRODUCTION

The Occupational Therapy Practice Framework (OTPF), which guides occupational therapy practice, states that participation in occupations is both the means to and measure of health for all individuals (AOTA, 2014). Occupational therapists facilitate engagement in occupations to help individuals regain and sustain their health. Active participation promotes adaptation to the environment, whereas passive or imposed participation does not (King, 1978; Schkade & Schultz, 1992). Participation is also a fundamental construct in the World Health Organization's revised International Classification of Functioning and Disability (WHO, 2001). When an individual's abilities to participate do not meet the demands of their environment and contexts the ICF describes this as a disability (WHO, 2001). Participation therefore is central to understanding and intervening in an individual's health and wellbeing.

Occupational therapists work with many children with special needs. Typically, pediatric occupational therapists work with and view children within the context of their families. Family-centered practice (FCP) is fundamental to occupational therapy with children (AOTA, 2004). Family members are interdependent and each member's characteristics, temperament and actions affect the quality of the interactions and ultimately the quality of development for the child (Sameroff & Fiese, 2000). Individual participation within the interdependent unit of the family can be disrupted as a result of the behavior of one of the family members, therefore, the assessment of all family

members' abilities to participate is an important component in the successful treatment of the child.

Occupational therapists treat an increasing number of young children with sensory processing abnormalities that are secondary to various developmental delays (DD) (Schaaf & Miller, 2005; Tomcheck & Dunn, 2007). The majority of research on sensory processing abnormalities focuses on children with autism spectrum disorders (ASDs), very little of which includes children younger than four years of age (Ben-Sasson, Hen, Fluss, Cermak, & Engel-Yeger, 2009; Rogers, Hepburn & Wehner, 2003). Although sensory processing abnormalities are not unique to children with ASDs, recent literature shows children with ASDs have more sensory processing difficulties than those with general developmental delays and those who are typically developing (Baranek, David, Poe & Watson, 2006; Rogers et al., 2003). Parents of children with ASDs identify increased levels of stress and disruption to family life and participation in routines as a result of these sensory abnormalities (DeGrace, 2004, Schaaf, Toth-Cohen, Johnson, Outten & Benevides, 2011). Furthermore, the abnormal sensory behaviors of these children are often the reason for referrals to occupational therapy (Watling, Deitz, Kanny & McLaughlin, 1999).

Young children with developmental delays also tend to exhibit more behavioral problems than their typically developing peers (Baker, Blacher, Crnic & Edelbrock, 2002). This is associated with increased parental stress in DD (Hastings, 2002; Lecavalier, Leone & Wiltz, 2006). Behavior problems are noted to create more family

disruption than the DD itself (Baker et al., 2003) and can make it difficult for therapists to provide interventions (Lane, Young, Baker & Angley, 2010).

Some literature suggests that behavior problems in children with DD might be driven by sensory abnormalities, particularly the behaviors seen in ASD such as sensory seeking behaviors, avoidance and a hypo-responsive presentation (Ashburner, Ziviana & Rodger, 2008; Lane, Baker & Angley, 2010; O'Donnell, Kartin, Nalty & Dawson, 2012; Tseng, Fu, Cermak, Lu & Shieh, 2011). These findings are supported by Dunn's (1997) Model of Sensory Processing that describes a continuum of neurological thresholds for recognizing and responding to sensory inputs, and one's ability to regulate the two. Dunn describes how children who demonstrate sensory avoiding behaviors have low neurological thresholds and resist changes to avoid confrontation with novel input from the environment. Alternately, children with high thresholds will seek out more of an input before the brain can recognize it and make use of it for generating a response. Dunn's (1997) model might explain how sensory processing abnormalities produce behaviors that are disruptive to families of children with DDs. However, there are very few studies examining potential links between sensory processing and maladaptive behaviors. This is particularly true for very young children.

The three purposes of this study were: 1. to identify whether or not there is a pattern of sensory-processing that may contribute to decreased parental participation in occupations, 2. to determine if there is a relationship between maladaptive behaviors (such as aggression, withdrawal, somatization, emotional over/under-reactivity etc.) and parent participation, and 3. to identify relationships between sensory processing patterns

and maladaptive behaviors in children who have been referred to occupational therapy for developmental delays, sensory processing concerns, or behavioral issues.

CHAPTER II

LITERATURE REVIEW

Participation

Participation in meaningful activities has been central to occupational therapy since its inception (Meyer, 1922, Reilly, 1962). The current Occupational Therapy Practice Framework 3rd Edition (OTPF, AOTA, 2014, p.S1) describes occupational therapy as, “the therapeutic use of everyday life activities (occupations) with individuals or groups for the purpose of enhancing or enabling participation in roles, habits, and routines in home, school, workplace, community, and other settings.” Occupational therapists work with people of all ages in a variety of settings using engagement in occupations as their interventions to promote wellness. Participation implies more than random activity, but one for which that person is motivated (Florey, 1969) and self-initiates (Yerxa, 1966), one that has an end product (either tangible or intangible), and is satisfactory to self and others (Schkade & Schultz, 1992). Participation in occupations reflects cultural values (Crepeau, Cohn, & Schell, 2003). Participation gives meaning to life (Hinojosa & Kramer, 1997). Active engagement promotes adaptation to the environment, whereas passive or imposed participation does not elicit adaptive responses (King, 1978; Schkade & Schultz, 1992). This is true for individuals of all ages including young children. Young children’s daily routines may include co-occupations (Zemke & Clark, 1996) with parents and caregivers due to their age and abilities.

The World Health Organization (WHO) has changed its paradigm of health from a focus on disability and disease to one of wellness and participation (WHO, 2002). The

WHO's International Classification of Functioning, Disability and Health, or ICF, provides a standard language and framework for the description of health for healthcare professionals (WHO, 2002). The ICF views disability as the result of the interactive process that occurs when a person's abilities are not matched to their environment or context (WHO, 2002). Moreover, the ICF holds that diagnosis alone is not an indicator of function or ability to participate, but recognizes that one's context can contribute substantially to decreased participation in life activities and subsequent disability. Environmental features can both negatively and positively impact an individual's functional capacity and ability to participate in life activities (health). Modification to these features has potential to increase their participation and health. Life activities as defined by ICF include: personal maintenance, mobility, exchange of information, social relationships, home life and assistance to others, education, work and employment, economic life, and community, social and civic life. The World Health Organization also holds that the healthy development of children is basic to overall societal health and that children's ability to function within their environment is essential to such development (WHO, 2006).

The Occupational Therapy Practice Framework is a "summary of interrelated constructs that describe occupational therapy practice" (OTPF, AOTA, 2014, p.s1). The OTPF states that health and wellbeing are maintained when "clients are able to engage in occupations and activities that allow desired or needed participation in home, school, workplace, and community life," (OTPF, AOTA, 2014, p.629). Occupational therapists assess and intervene in areas similar to the ICF including: areas of occupation, client

factors, performance skills, performance patterns, context and environment, and activity demands (OTPF, AJOT, 2014). Occupational therapists often act as agents of the environment and may choose to alter the features of an individual's environment to enhance self-directed participation (Schultz & Schkade, 1992). Both the OTPF and The International Classification of Functioning, Disability and Health (ICDF) are frameworks that guide practice, dialogue, and research for occupational therapists. Both encourage a holistic view of the person. ICF encourages assessment of body functions, structures, impairments, and activities and activity impairments, participation and environmental factors to determine the "gap between capacity and performance" (WHO, 2002, p.12). Occupational therapists assess the complex features of an individual and their various contexts (cultural, physical, social, temporal, and visual) that enable or detract from engagement. The end goal of both is to enhance individual participation in daily occupations. Therefore, the definition of health for all individuals is the ability to successfully participate in occupations within one's particular context and environments.

Family Centered Practice

The History of Family-Centered Practice (FCP)

Family-centered Practice (FCP) has steadily gained acceptance in healthcare since its development over 70 years ago. In 1959, Carl Rogers proposed a model of client-centered treatment that includes viewing clients of all ages as people of worth who are capable of self-direction (Wexler, 1974). In particular, he posited that children have two basic needs: positive regard from other people and self-worth, both of which develop in relationship with the parent (Rogers, 1951). The model describes the mutual influence of

treatment/intervention, family dynamics, function and participation in social life (Wexler, 1974). From Rogers' work, a general movement toward parent advocacy for children evolved. In the 1960's the Association for the Care of Children's Health adopted core features of Roger's model by stressing the importance of family to a child's wellbeing (Rosenbaum, King, Law, King & Evans, 1998). In his Ecological Theory, Bronfenbrenner (1979) adds the dimensions of seeing a child as a member of a family, an extended family, and a community, all of which exert influence over one another. He emphasizes that the parent-child dyad is of primary importance in normal development (Bronfenbrenner, 1979). This trend was formalized when the United States Senate passed the Education for All Handicapped Children Act Amendments of 1986, which legalized the family role as advocate and equal participant in their child's healthcare team (Lawlor & Mattingly, 1998).

Modern Family-Centered Practice

FCP has gained significant support in children's health with several models developing during the 1980's and 1990's. MacKean, Thurston, & Scott's 2005 review of FCP models reports six concepts which are common to models of family centered practice. These six concepts include:

- 1) The family is the constant feature and the primary source of strength and support in a child's life and must be recognized as such.
- 2) Family uniqueness and diversity should be acknowledged and respected
- 3) Parents should be recognized as the experts on the child and the family unit.

- 4) Intervention should be based on family strengths, not on the identification of family weaknesses.
- 5) Family-centered treatment should be truly collaborative between clinicians and parents.
- 6) Family-centered treatment should provide family-to-family support, and networking, to meet the emotional and financial needs of families.

FCP was first described in Early Childhood Intervention (ECI) as a philosophy as well as a model of intervention for children aged birth to three. In the model the family is central to the ECI process and interventions are based on and enhance family strengths (Rosenbaum, King, Law, King & Evans, 1998; Trivette & Dunst, 2005). There is an emphasis on parent training, empowerment and collaboration with medical professionals (Law, Darrah, Pollock, King, Rosenbaum, Russell, & Watt, J. 1998; Wayman, Forte & Ashland, 2003). There is also recognition that the characteristics, temperament and actions of both the child and caregiver affect the quality of the transaction and ultimately the quality of development (Sameroff & Fiese, 2000). Recent literature confirms that the family context exerts the most powerful influence on the development of children (Dunst, Trivette, Humphries, Raab & Roper, 2001; Hinojosa, Sproat, Mankhetwit, & Anderson, 2002; OSEP, 2008; Rosenbaum, King, Law & King, 1998). Dunst et al. (2002) add that the primary role of clinicians is to help parents improve the quality and quantity of a child's development-enhancing experiences. FCP has been shown to enhance: child outcomes (Dunst, 2002; Morris & Taylor, 1998); parent satisfaction (Law et al., 2003;

O'Neil, Palisano, & Westcott, 2001; Van Schie, Siebes, Ketelaar, & Vermeer, 2004), and parent participation (Dunst, Boyd, Trivette, & Hamby, 2002) all of which are goals of occupational therapy.

IDEA, Part C (Early Childhood Intervention) and FCP

In 1986 the Individuals with Disabilities Education Act (IDEA) Part C (Pub. L.108-446, 20 U.S.C. 1400 et seq.) established a state administered program to serve children from birth to their third birthday diagnosed with developmental delays, physical or mental conditions, and a high probability of future developmental delays. IDEA supports a family-centered therapy approach and requires that the family be the focus of intervention rather than the child with the disability (idea.ed.gov). By 1993, the Department of Early Childhood recommended using a family-centered model in all ECI practice (Odem & McLean, 1993; Vincent & Beckett, 1993). The Individualized Family Service Plan (IFSP), which drives interventions in ECI demonstrates the family-centered nature of the IDEA and the Department of Early Childhood recommendations. The IFSP is defined as “family-directed assessment of the resources, priorities, and concerns of the family and the identification of the supports and services necessary to enhance the family’s capacity to meet the developmental needs of the infant or toddler” (IDEA, Sec. 636[a][2]). Furthermore, the Individuals with Disabilities Education Improvement Act of 2004 (Pub L. 108–446) mandated the involvement of parents and caregivers to the greatest extent possible.

Additional work towards family centered interventions in ECI was done by the Office of Special Education Programs, the administrative component of the U.S.

Department of Education's programs for all children with disabilities. In 2008, the Office of Special Education Programs (OSEP) convened a working group of subject matter experts to create a family-centered doctrine for ECI. This workgroup formalized federal endorsement of family-centered intervention in ECI when it set forth its Key Principles:

- 1) Infants and toddlers learn best through every day experiences and interactions with familiar people in familiar contexts.
- 2) All families, with the necessary supports and resources, can enhance their children's learning and development.
- 3) The primary role of the service provider in early intervention is to work with and support the family members and caregivers in a child's life.
- 4) The early intervention process, from initial contacts through transition, must be dynamic and individualized to reflect the child's and family members' preferences, learning styles and cultural beliefs.
- 5) IFSP outcomes must be functional and based on children's and families' needs and priorities.
- 6) The family's priorities needs and interests are addressed most appropriately by a primary provider who represents and receives team and community support.
- 7) Interventions with young children and family members must be based on explicit principles, validated practices, best available research and relevant laws and regulations (OSEP, 2008).

Clinical Practice and FCP

In spite of the apparent support for FCP in the allied health fields and the federal government, confusion remains as to how to define and implement FCP in practice, and to further insure that therapists are using FCP in treatment. Parents involved with ECI report a gap between the services they receive and those services that they need to be successful with their child (Summers et al., 2007; Turnbull, Summers, Turnbull et al., 2007). Research from the The National Early Childhood Technical Assistance Center's (2004) research on the provision of ECI services notes that there has been an overall increase in child-based services on Individual Family Service Plans (IFSP) and a decrease in family-based services, in spite of governmental direction to do otherwise. Therapists are working more collaboratively with parents to support family choice in treatment, but spend less time helping them access supports and services available to them (Turnbull, Summers, Turnbull et al., 2007). OSEP's 2011 revision of ECI policy requires programs to insure parents: know their rights; are able to communicate their child's needs; and, are able to help their child develop and learn (OSEP, 2011). The policy does not make ECI programs or providers responsible for family services, or the families' ability to access them (Epley, Summers & Turnbull, 2010). Epley et al. (2010) conclude their review noting that the family must be central to ECI interventions and that family-based interventions are needed for the effective care of children with disabilities as described in the Key Principles of OSEP.

FCP in Occupational Therapy With Young Children

Occupational therapists evaluate and treat young children birth to three years old with disabilities in the context of their families and caregivers. The purpose of therapy is to “enhance the family’s capacity to care for the child’s health and development within daily routines and natural environments,” (AOTA, 2011, p. 5). Family-centered occupational therapy reflects the profession’s belief in the mutual impact children with disabilities and their parents have on one another’s ability to participate in daily occupations (Jaffe, Humphrey, & Case-Smith, 2010). Furthermore, the American Occupational Therapy Association describes family-centered interventions that support and strengthen family and child wellbeing as one of its research priorities (AOTA, 2014).

There is little research however that demonstrates the usage and effectiveness of FCP in occupational therapy. Fingerhut et al.’s (2013) recent qualitative study on therapists’ perception of their use of FCP reveals that most understand its principles, but have difficulty operationalizing the concepts in most practice areas outside of home health (interventions that occur in the client’s home). Home health (primarily ECI settings) is noted to be more conducive to the use of family centered principles possibly due to the federal guidelines (Fingerhut et al., 2013). In her 2003 article, DeGrace asserts that while the OT profession claims to be family-centered it remains unable to describe how it is “(a) addressing the occupations of the family unit, (b) measuring change within the family unit, and (c) helping the family unit to meaningfully participate in everyday life.” (p.347). She continues to describe how occupational therapy’s ability to address family occupations can promote and restore health to all its members and can contribute

to a healthier society (DeGrace, 2004). Further research in FCP is needed to help validate its efficacy in occupational therapy intervention and ultimately enhance the profession's understanding of and implementation of its elements. The identification of child-based issues that correlate with decreased parent participation can help focus these efforts.

Parenting a Child with Special Needs

Evidence shows that raising a child with special needs can be more demanding and stressful than raising a child who is typically developing (Baker, et al., 2002; Baker et al., 2003; Hastings, 2002; Tomanik, Harris & Hawkins, 2004; Spratt, Saylor & Macias, 2007). Specifically, parents report higher levels of stress and depression, and lower levels of general wellbeing than those raising typically developing children (Benson, 2006; Hastings & Brown, 2002; Montes & Halterman, 2008). Children with special needs often require more attention, time and care as a result of delays in the development of skills than typically developing children (Breslau, Staruch, & Mortimer, 1982; Roberts & Lawton, 2001). Children with special needs may require more parent attention and assistance in multiple areas of life including the completion of self-care activities, social participation, and education (Schaaf, et al, 2011). There is evidence that the more attention the child with a developmental delay requires, the more stress the parent feels (Leonard, Johnson & Brust, 1993). Moreover, parents often feel a lack of competence in raising a child with special needs compounding their stress (Frey, Greenberg, & Fewell, 1989; Krauss, 1993).

The effects of the stress that comes with parenting a child with special needs appear to be widespread. The pervasive demands of caregiving for a child with special needs can lead to role confusion (McGuire, Crowe, Law & Van Leit, 2004) and role loss, which contributes to financial strain (Lewis, Kagan & Heaton, 2000; Montes & Halterman, 2008). Parents are noted to have decreased participation in self-care and leisure (McGuire, Crowe, Law, & VanLeit, 2004). The stress can even result in decreased physical health and quality of life (Allik, Larsson, & Smedje, 2006). Emerson (2003) adds that parents of children with developmental disabilities have impaired physical functioning and exhaustion that results in lack of attention to their own needs. Neglecting one's own occupational needs is associated with feelings of isolation, stress, and dissatisfaction with life when parenting a child with special needs (Duarte, Bordin, Yazigi, & Mooney, 2005). Parents raising a child with special needs are at risk for decreased or altered abilities to participate in desired or needed occupations, from self-care to career choices.

Parenting a Child With Autism Spectrum Disorder (ASD)

Raising a child with ASD presents some unique challenges and there is an increase in research into this population. Parents raising a child with Autism Spectrum Disorder (ASD) report higher levels of stress than parents of typically developing children and those with other developmental disabilities (Fombonne, Simmons, Ford, Meltzer & Goodman, 2001). This includes children with Down Syndrome, Fragile X, and Cerebral Palsy (Abbeduto, 2004; Blacher & McIntyre, 2006; Eisenhow, Baker, & Blacher, 2005; Kaseri & Signman, 1997). Families of children with ASD have more

difficulty maintaining routines and participation, in and outside of the home (Larson, 2006; Schaaf et al., 2011). Parents with a child with ASD spend 50% more time providing for the needs of their child than those of typically developing children (Tunali & Power, 2002). This extra time does not appear to be spent in social, cultural or leisure pursuits because families with a child with ASD tend to spend significantly less time in these activities than those with typically developing children or those with Down Syndrome (Sanders & Morgan, 1997). Parents of children with ASDs often change work patterns and curb participation in activities as a result of the child's unusual sensory and behavioral needs. They can have difficulty obtaining appropriate childcare and resort to shifting their life and work schedules so that one parent is with the child at all times (Montes and Halterman, 2008). Studies show that behavior problems are more severe in ASDs than in other DDs (Eisenhower, Baker & Blacher, 2005; Herring et al., 2006). Behavioral problems in ASDs also tend to be broader than in DDs and can encompass self-injury, non-compliance, aggression, and destructive and stereotypical behaviors (Baghdadli, Pascal, Grisli & Aussiloux, 2003; McClintock, Hall & Oliver, 2003)

Several recent qualitative studies from occupational therapy help to illustrate the lived experiences of parents raising a child with ASD. In 2004, DeGrace used in depth interviews to explore the significance five families gave to their ability to participate in daily occupations while raising a child with ASD. Questions focused on family structure, the meaning that daily activities have to them, and the identification of moments when they felt like a family. Using a phenomenological approach the author discovered four themes. The first is that ASD is viewed as a distinct entity to the family around which

their lives revolve. They describe the demands of ASD as incessant and extremely stressful. ASD often dictates where, when, and how they can complete occupations in and outside of the home. The families feel robbed of experiences typical families share and were reluctant to plan or dream about the future. They describe a need to “occupy and pacify” (DeGrace, 2004, p.547) the child with ASD to manage his or her sensory responses or behaviors. These families had difficulty identifying moments that felt authentically family-like and described grieving for a family life they would not have.

Larson’s 2006 study of nine mothers raising boys with ASD finds that there is comfort and predictability in making and trying to adhere to routines in family life. If daily activities remain the same every time, then the children are better able to participate willingly and the task can be completed. This rigid adherence provides a sense of security to that child, but also blocks spontaneous activity by the rest of the family. The mothers add that when a task becomes too challenging or something goes wrong within it, then the rigid routine around the activity becomes a source of frustration requiring even more adult supervision and assistance. Mothers describe altering their own and other children’s schedules to maintain the routine of the child with ASD. They forego their own participation in desired activities to avoid potential triggers to the child’s behavior or unhappiness. When this happens the mothers describe a disruption to the entire emotional state of the family.

In 2010, Kahanek, Burroughs, Wright, Lemanczyk & Darragh also used a phenomenological approach to explore common experiences and coping strategies of mothers raising a child with ASD. They inquired about stressors and effective and

ineffective strategies for dealing with these. Some themes that emerged for positive coping were: maintenance of personal time in the midst of an intense and full daily schedule; the ability to plan ahead to meet the demands of the whole family and, in particular, for the child with ASD's sensory and behavioral needs; the ability to share the workload with a spouse so that personal time and planning can happen; and to be aware of the resources, laws and services that are available to them. Parents find that being aware of the services that are available to them gave them a significant feeling of empowerment (Kuanhek et al., 2010).

Parenting a Child with Special Needs and Maladaptive Behaviors

Parental feelings of elevated stress, decreased satisfaction with daily life and ability to participate in one's own occupations seem exacerbated when the child has a DD and behavioral problems (Baker et al., 2003; McGuire, Crowe, Law, & Van Leit, 2004; Neece, Green & Baker, 2012). In fact, some literature suggests that the behavior associated with a developmental delay is more difficult for parents to manage than the delay itself (Baker et al., 2002; Walker, Van Slyke, & Newbrough, 1992). Also, there is a cyclical nature to this in family systems: child negative behavior results in increased parental stress, stress leads to less involved parenting, less involved parenting provokes more child negative behavior (Baker et al., 2003; Lecavalier, Leone, & Wiltz, 2006). The bi-directionality of child behavior problems and parenting stress continues to gain support in the literature (Neece, 2014; Neece, Green & Baker, 2012; Osborn & Reed, 2009). Hastings and Brown (2002) continue to describe evidence from their study that shows self-efficacy, or feeling that one can successfully parent their child, is a major

component of understanding a child's behavior problems and parental mental health.

Maladaptive behaviors noted in the literature include both internalizing and externalizing behaviors that are clinically significant compared to typically developing children (Baker et al., 2003; Eisenhower, Baker & Blacher, 2005; Lecavalier, Leone & Wiltz, 2006).

Internalizing and externalizing behaviors are constructs with origins in the field of psychology (Achenbach, 1979). Externalizing behaviors are those behaviors that are directed outward towards the external environment and consist of disruptive, hyperactive, and aggressive behaviors (Hinshaw, 1987). Internalizing behaviors are those directed towards the child's internal or psychological self and manifest themselves in withdrawn, anxious, inhibited, and depressive behaviors (Campbell, Shaw & Gilliom, 2002).

Children with DD demonstrate both internalizing and externalizing behaviors that are significantly higher than those of typically developing children (Baker, Blacher, Crnic & Edelbrock, 2002; Emerson & Einfeld, 2012; Tonge & Einfeld, 2003).

Maladaptive Behaviors in ASD

Although maladaptive behaviors are not unique to ASD much of the recent literature focuses on these children's behaviors. The DSM V (APA, 2013) diagnosis of ASD requires an individual to display symptoms in two areas: 1) persistent deficits in social interaction skills (i.e. difficulty understanding verbal and non-verbal communication, inappropriate responses to social situations, poor eye contact, and difficulty adjusting behavior to fit different contexts); and, 2) repetitive and restricted behaviors (RRBs) and interests (such as insistence on sameness and routine with extreme distress reactions to even small changes, fixation on unusual objects, motor stereotypies

such as hand flapping or self-injury, and atypical responses to sensory input). RRBs are defined by their inappropriate and generally inflexible nature and often include hand-flapping, self-injury and lining up of toys or items in a precise manner (Boyd, McBee, Holtzclaw, Baranek, & Bodfish, 2009).

Parenting a Child With Special Needs and Sensory Processing Abnormalities

The presence of sensory processing abnormalities in children with disabilities can also affect family life. Sensory processing is commonly understood to mean the process by which the brain receives and makes use of all forms (tactile, auditory, visual, taste etc.) of sensations to generate adaptive behaviors in response to the environment (Miller & Lane, 2000). Much of the research on this topic occurs in ASD due to the high rate of sensory processing abnormalities seen in this group of children (Ben-Sasson, Hen, Fluss, Cermak, & Engel-Yeger, 2009; Rogers, Hepburn & Wehner, 2003). Between 45% and 96% of children with ASDs present with sensory difficulties (Ben-Sasson et al., 2009; Lane, Young, Baker & Angley, 2010). Sensory difficulties are so pervasive that the American Psychological Association (2013) now includes hypo- or hyper-reactivity to sensory input as a distinguishing feature of ASDs because of the common manifestation in the ASD population, as noted in Subsection B of diagnosis 299.00 (APA, 2013). Estimates of the rate of sensory processing abnormalities in children with various disabilities vary between 40-88% (Ahn, Miller, Milberger, & McIntosh, 2004; Kientz & Dunn, 1997; Talay-Ongan & Wood, 2000).

Research on abnormal sensory processing is limited and has not clarified any specific sensory presentations that are unique to specific diagnoses (Baranek et al., 2006;

Rogers & Ozonoff, 2005). Several studies show that children often present with co-morbid sensory under-responsivity and over-responsivity, one of the most identified confounders of research in this area (Baranek, 2002; Baranek et al., 2006; Ben-Sasson et al, 2009; Greenspan & Wieder, 1998). It remains unclear as to whether sensory abnormalities evoke specific behavioral issues, such as repetitive and restrictive behaviors and this warrants further exploration (Baker, Lane, Angley & Young, 2007; Miller, Coll & Schoen, 2007; Rogers et al., 2003).

Schaaf, Toth-Cohen, Johnson, Outten & Benevides (2011) looked specifically at sensory-related behaviors in four children with ASD and their effect on family routines. They used a semi-structured interview process to inquire about family routines, occupations in which they participate inside and outside of the home, family roles, and the child's sensory processing difficulties. They also used the Sensory Processing Measure (SPM, Parham et al. 2007), and a Home Form, a parent report form, to identify the parent's view of quality and intensity of the child's sensory processing abilities. All of the children in the study demonstrated sensory processing dysfunction on some level in all areas of the SPM. Themes that emerged from the qualitative interviews were: the need to maintain flexibility in their schedule so the child's sensory responses can be managed and the family can continue to participate in desired activities (particularly outside of the home); the need to stay mostly in familiar environments due to the unpredictability of the child's responses to the features of a novel environment; difficulty completing family activities due to the child with ASD's unique needs (such as food preferences or the inability to sit for prolonged periods of time); sibling difficulties (such

as an inability to spend quality time with other children because sibling's needs come second) due to the intensity of needs of the child with ASD; and the need to be vigilant at all times about how the environment is affecting the child with ASD's ability to self-regulate sensory experiences. They summarize their study noting that sensory-related behaviors have a significant and far-reaching impact on all family routines and occupations, and the ability to participate in them. The constant need to plan, modify plans, and maintain a high level of vigilance alters the family experience in a way that families without a child with ASD would typically have to.

Bagby, Dickie and Baranek (2012) used a grounded theory approach to research the lived experiences parents of children with and without ASD and sensory processing issues. They used open-ended questions and specific prompts. Results showed that the sensory experiences affected both what families chose to do and not to do, including avoiding or approaching places and situations that might be challenging for the child with sensory issues. Furthermore, families with a child with ASD identified a significantly greater need for planning and a willingness to change those plans quickly should the child be unable to tolerate the sensory stimulation in an environment. Some families felt that their child's sensory experiences lead them to have unique feelings of togetherness. Others reported that sensory experiences lead them to participate in different activities thereby preventing a feeling of family cohesion. Parents of children with ASD reported difficulty making a cognitive connection with their child and feelings of incompetence due to this lack of connection and shared experiences.

Researchers suggest that more rigorous studies on sensory abnormalities are warranted (Ben-Sasson et al., 2009; Rogers & Ozonoff, 2005; Schaaf, Toth-Cohen, Johnson, Outten & Benevides, 2011). A primary recommendation is for research with children who have homogenous sensory presentations (Ben-Sasson et al., 2009; Dawson & Watling, 2000; Schaaf, Hunt & Benevides, 2012; Schaaf & Miller, 2005). Since sensory processing difficulties of children with disabilities have a significant effect on the participation of their parents, the identification of sensory processing patterns that trend with decreased participation could facilitate such research studies.

What is the Relationship Between Maladaptive Behaviors and Abnormal Sensory Processing?

Maladaptive behaviors have been attributed to sensory processing problems in occupational therapy literature for many years (Ayres, 1972; Ayres, 1979; Baker, Lane, Angley & Young, 2008; Baranak, 1999; Dunn, Myles & Orr, 2002). Theories of sensory processing and integration propose that the adequate and efficient processing of inputs from the environment results in adaptive behavior (Ayres, 1972; Dunn, 1997; Johnson-Ecker & Parham, 2000). Conversely, the theories suggest that dysfunctional sensory processing evokes maladaptive behaviors that are viewed as attempts to regulate environmental input (Baranek, Foster & Berkson, 1997; Dunn, 1997). Dunn's 1997 model of sensory processing and its instruments are commonly used in occupational therapy assessment and research (Ashburner, Ziviani & Rodger, 2008; Schaaf et al., 2013; Wiggins et al., 2009). The model creates a classification system of specific

response patterns of individuals with sensory processing abnormalities. These are based on neurological and behavioral thresholds and include:

1.) *Low Registration* describes the child who has difficulty registering stimuli from the environment due to high neurological thresholds and therefore presents as disinterested in what is happening around him or her. These children may be perceived as withdrawn, difficult to engage, or self-absorbed. Dunn notes that these children engage in RRBs “presumably to increase the stimuli so they can “fully experience” the activities” (Dunn, 1997, p. 31).

2.) *Sensation Seeking* describes the child with high neurological thresholds that is trying to counteract this by seeking more sensory experiences. He or she may present with excessive movement, noise-making, touching or mouthing behaviors. They may be perceived as extremely active, risk-taking, and impulsive (Dunn, 1997).

3.) *Sensory Sensitivity* represents the child who cannot screen out stimuli due to low neurological threshold therefore, can present as distracted and hyperactive. They can be perceived as fearful, resistant to activity or even defiant. These children often cannot participate in traditional learning activities due to their sensitivities (Dunn, 1997).

4.) *Sensation Avoiding* represents a child with low neurological thresholds that tries to counteract this by avoiding environmental input. He or she may present as insistent on routine or rituals to help avoid unexpected input and may withdraw or resist activities.

The model is based on neurophysiological concepts, but Dunn (1997) notes that it must be tested. It is evident in this model that behaviors are viewed as outward expressions of underlying sensory processing issues.

Research on the Relationship Between Sensory Processing Abnormalities and Maladaptive Behaviors

There has been a growing interest in research into the relationship between sensory processing and behavior in the past two decades. The suggestions of occupational therapy's sensory-processing theories seem to be borne out in some intervention studies that show a decrease in maladaptive and an increase in adaptive behaviors following sensory-based interventions (Ayres & Tickle, 1980; Case-Smith & Bryan, 1999; Linderman & Stewart, 1999; Mulligan, 2003). However, others show no decrease in maladaptive behaviors following sensory-based interventions (Hoehn, & Baumeister, 1994). RRBs have been strongly associated with sensory symptoms (Rogers, Hepburn & Wehner, 2003; Wiggins, Robins, Bakerman & Adamson, 2009). A hyper-responsive sensory presentation (over-reacting to sensory stimulation from the environment) showed significant association with repetitive behaviors in children with both ASD and DD (Baranek et al., 1999; Boyd, et al., 2010). Hyper-responsivity has been shown to trend with avoidance in self-care (Jasmine et al., 2009), with motor stereotypies (Baranek et al., 1997; Gal et al., 2009) and with anxiety (Pfeiffer, Kinnealey, Reed & Hertzburg, 2005). Sensory hypo-responsivity has been associated with poor attention to task (Ashburner, Ziviani & Rodger, 2008). Some studies show that young children with ASD display significantly more hypo-responsive (under-reacting to environmental stimuli) than DD or typical children and therefore are more sensory-seeking (Ben- Sasson et al., 2008; Rogers, Hepburn, & Wehner, 2003; Watling, Dietz, & White, 2001). However, in their 2005 systematic review of 75 empirical and concept

papers on ASD, Rogers and Ozonoff (2005) conclude that there is no solid evidence that the theories of under-arousal/over-arousal, habituation and neurological thresholds and unusual behaviors in ASD are attempts to regulate abnormal sensory responses.

Recommendations they make for future studies of sensory concerns include the use of narrower participant age groups and the use of at least two sensory modalities so that a fuller picture of sensory abnormalities and their impact on children emerges.

In 2012, the American Academy of Pediatrics' (AAP) published a statement on sensory integration theory and the treatment of children with DD and behavioral disorders. It cautions that there is little conclusive evidence that sensory processing issues exist apart from other developmental and behavioral disorders. The AAP states that clinicians must complete more methodologically rigorous outcomes studies that include: consistent outcome measures, participant groups with more homogenous sensory symptom presentations, and family factors that impact treatment (AAP, 2012).

Nonetheless, the literature indicates that there is a high incidence of children with DDs with sensory processing abnormalities, that these co-occur with maladaptive behaviors in many cases, and prevent full participation in the occupations of many children and their families. It is evident that further research is needed to determine if there are relationships between the various facets of behavior (internalizing/externalizing) and sensory processing (hyper/hypo-responsivity) areas.

What Mitigates Stress in Parents Raising a Child With Special Needs?

There are many factors that appear to mitigate stress for those parenting children with developmental delays. Professional intervention in naturalistic settings, such as

ECI, can help parents to better understand the child's disability and learn about resources available to them, which can decrease stress (Koegel, Bimbela & Schreibman, 1996) and depression (Bristol, Gallagher, & Holt, 1993). Social supports outside of the family also decrease stress for parents (Park, Turnbull & Rutherford, 2002). Society members who show understanding of the child's disability helps mitigate stress (Gupta, 2007). Having healthy and active coping strategies are some of the more universal methods of mediating stress and is particularly true of families raising a disabled child (Grant & Whittell, 2000; Jones & Passey, 2005). Reframing the disability or delay can enhance parental coping. Parents who are able to see the positive aspects and results of raising a child with a disability seem to cope better with the elevated stress of their lives (Hastings et al., 2005; Tway, Connelly & Novak, 2007). Therefore, the identification of which child factors interfere with parent participation and how they do so become critical parts of the occupational therapy evaluation and intervention process.

Significance and Questions

Occupational therapy posits that health is measurable, maintained and re-established through participation in occupations. When therapists intervene with young children, they do so in the context of the family system, per the Occupational Therapy Practice Framework, which guides occupational therapy practice (AOTA, 2014). Families are interdependent and the behaviors and needs of one member affect all family members (Jaffe, Humphrey, & Case-Smith, 2010). Raising a child with a DD often results in increased stress and decreased participation in many life occupations of parents and caregivers (Baker et al., 2003; McGuire, Crowe, Law, & Van Leit, 2004). Since

young children are dependent on their parents for most of their needs and access to development-enhancing opportunities parental health is a primary focus when intervening with this age group. Therapists can identify which issues are constricting or preventing parent participation in order to effectively intervene. Qualitative literature shows that both behavioral problems and abnormal sensory processing cause significant stress and create barriers to participation for parents (DeGrace, 2004; Schaaf, Toth-Cohen, Johnson, Outten & Benevides, 2011). It remains unclear which behaviors and sensory processing abnormalities are more disruptive to parental participation. The relationship between sensory processing abnormalities and maladaptive behaviors has only recently been addressed (Rogers, Hepburn & Wehner, 2003).

This study sought to add to the growing body of literature on the effects of sensory processing abnormalities and maladaptive behaviors on parent participation in their chosen occupations. It did so by comparing three instruments designed to measure the constructs of parent participation, sensory processing in young children, and behavior in young children. It seeks to address the following questions:

- Do levels of sensory processing as measured by the Infant Toddler Sensory Profile (ITSP, Dunn & Daniels, 2002) correlate with parent participation as measured by Life Participation of Parents (LPP, Fingerhut, 2005)?
- Do levels of maladaptive behavior, as measured by the Child Behavior Checklist (CBCL, Achenbach & Rescorla, 2000), correlate with levels of parent participation as measured by the LPP (Fingerhut, 2005)?

- Does the pattern of sensory presentations as measured by the ITSP correlate with maladaptive behaviors as measured by CBCL (Achenbach & Rescorla, 2000)?

CHAPTER III

METHODOLOGY

Methods

The purpose of this research was to explore relationships that may exist between three entities: first between abnormal sensory processing in young children and their parents' participation; next, between maladaptive behaviors in young children and their parents' participation; and, finally between the relationship between abnormal sensory processing and maladaptive behaviors in young children. The study met specifications set forth by Texas Woman's University (TWU) Institutional Review Board (IRB) through an Institutional Authorization Agreement with the University of Texas Medical Branch.

Participants

The participants for this study were parents and caregivers with a child age three years and younger who receives ECI or outpatient pediatric occupational therapy for developmental delays, ASDs, identified or suspected sensory processing abnormalities, or behavioral issues. Exclusion criteria included parents of children with an identified co-morbid genetic disorder such as Fragile X, children with cerebral palsy, parents of children without suspected or identified sensory processing abnormalities, families outside the state of Texas, parents who do not speak either English or Spanish.

Instruments

The Life Participation of Parents-LPP (Fingerhut, 2005) is a 23-item parent questionnaire designed to measure parent ability to participate in life occupations while raising a child with special needs. The purpose of the tool is to help clinicians: determine

a need for further evaluation; identify specific need areas; develop specific interventions; and, measure progress after intervention has occurred (efficacy). It is based on the Occupational Adaptation frame of reference that uses personal efficacy and satisfaction as primary indicators of quality of life (Schkade & Schultz, 1992; Schultz & Schkade, 1992). The LPP uses a 5-point, Likert scale with a range of answers *strongly agree*, *agree*, *both agree and disagree*, *disagree*, and *strongly disagree*. At the end of each question there is space available for optional comments or open-ended answers. The LPP showed good internal consistency ($\alpha=.90$) and test-retest reliability ($r=.89$) in recent analysis (Fingerhut, 2013).

The Infant Toddler Sensory Profile (Dunn & Daniels, 2002) for children seven to 36 months of age, is a 48-item parent/caregiver questionnaire designed to measure sensory processing abilities as seen in daily life experiences. Parents rate the frequency of their child's behaviors on a 5-point, Likert scale that ranges from *almost always*, *frequently*, *occasionally*, *seldom*, to *almost never*. The frequency of behaviors is calculated for sections including: Auditory, Visual, Vestibular, Tactile, and Oral Sensory. Scores are then grouped into four quadrant scores of Low Registration, Sensation Seeking, Sensory Sensitivity, and Sensation Avoiding. Scores are interpreted according to age norms and placed into the following categories: definitely different, less than others ($> 2 SD$); probably different, less than others ($1 SD$ to $2 SD$); typical performance ($\pm 1 SD$); probably different, more than others ($-1 SD$ to $-2 SD$); and, definitely different, more than others ($< -2 SD$). Internal reliability for the Infant Toddler Sensory Profile ranged from 0.42 to 0.86 (Dunn 2002). Test-retest reliability for the Infant

Toddler Sensory Profile ranged from 0.74 for quadrant score to 0.86 for sensory processing section scores (Dunn 2002).

The Child Behavior Checklist for Ages 1.5-5 (Achenbach & Rescorla, 2000) is a 99-item parent questionnaire that provides descriptors of behavioral, emotional, and social problems with which preschool children may present. Respondents, who are typically parents or caregivers, rate each descriptor on the frequency noted in their child on a three-point scale between: 0, *not true*; 1, *somewhat or sometimes true*; and 2, *very true or often true*. The CBCL/1.5-5 yields t-scores for seven *syndrome scales* that include: Emotionally Reactive; Anxious/ Depressed; Somatic Complaints; Withdrawn; Attention Problems; Aggressive Behavior; and Sleep Problems. The syndrome scales can be combined to create Internalizing Behavior Scores (Emotionally Reactive, Anxious/Depressed, Somatic Complaints, and Withdrawn scores combined), and Externalizing Behavior Scores (Attention problems and Aggressive Behavior scores combined). Items are scored according to Diagnostic and Statistical Manual V scales in the categories: Affective Problems, Anxiety Problems, Autism Spectrum Problems, Attention Deficit/Hyperactivity Problems, and Oppositional Defiant Problems. These data were not used in this study. CBCL 1.5-5 yields scores in the “borderline” range, which indicates concern about the behavior, but not at clinical levels. There are blank spaces for parents/caregivers to add information, ask questions, describe what concerns them most, and note what they like about the child. These data were not used in this study. The CBCL/1.5-5 shows reliability between 80’s-.90’s for all scales. The

CBCL/1.5-5 reports construct validity as between .56 to .77, when correlated with the Richman Behavior checklist.

Procedures

Institutional Review Board approval was obtained prior to initiating this research. Occupational therapists and clinic directors who work in ECI and outpatient pediatrics were approached to help identify and recruit parents who meet the inclusion criteria. A total of 15 therapists were educated on the purpose of the project and how to instruct and direct parents/caregivers to complete the forms as per the administrative procedures for each tool. Pre-coded packets were delivered to treating occupational therapists containing the following:

- Consent to participate
- The LPP (Fingerhut, 2005)
- The Infant Toddler Sensory Profile (Dunn & Daniels, 2002)
- Child Behavior Checklist (Achenbach & Rescorla, 2001)
- Return envelope for participant and local therapist to seal completed forms

Local occupational therapists or the primary investigator issued the coded protocols and packets to parents recruited to participate and who had read and signed an informed consent form. Therapists or PI instructed parents on how to complete the forms, excluding any personally identifiable information. Demographic information sections of the ITSP and the CBCL 1.5-5 were blacked out to protect participant confidentiality and avoid repetitive data collection. Therapists were asked to complete a brief demographic sheet that accompanies the LPP to provide the researcher with the date

the questionnaire was completed, the relationship of the person completing the form to the child, the child's age and gender, the caregiver's age, treatment diagnosis (if known), the primary language spoken in the home, and the ethnic background of the person completing the form. Parents completed all three questionnaires and returned all forms in the envelope provided to the therapist. The three questionnaires took approximately sixty to seventy-five minutes to complete. Parents who required more time were asked to complete the forms in a second therapy session. The therapists returned the envelope to the researcher when completed. The questionnaires were scored and the data entered into IBM® Statistics® 23 (SPSS) on a password-protected computer. No personally identifiable information was included on the coded protocols that were returned to the researcher. The analysis was made on coded data only.

Analysis

Frequency data were tabulated on participants including gender, age of caregiver and child, role of person completing the questionnaires, diagnosis, ethnic background, ITSP, CBCL, and LPP. Demographic data are reported. Normal curve histograms and Quantile-Quantile (Q-Q) plots were created to identify any obvious relationships or trends in the data, to insure that the requirements of linearity were met, and to check for data entry errors and outliers. Four participants were removed because of large sections of data missing from their questionnaires. A power analysis based on the different sections of the ITSP revealed that an *n* of 57-83 would be needed to obtain statistical power at the recommended .80 level. However, given the highly specific inclusion criteria of this study and difficulties recruiting parents of special needs children, an *n* of

30-40 participant families was established as the goal. Data analysis was completed on a total of 43 participants.

CHAPTER IV

RESULTS

Frequency Data

A sample of Forty-three parent/grandparents and fifteen occupational therapists participated in the study. Participants came from south Texas ECI centers and private, outpatient clinics. The majority of respondents were the children's mothers (39, 86%), followed by their fathers (3, 9.3%), and custodial grandparents (2, 4.7%). Parents were predominately under 30 years of age (21, 48.8%) or 30-50 (20, 46.6%) years of age (46.5%). The grandparent participants (2, 4.7%) were over 50 years of age. The mean age of the children was 29.5 months, with a range of 18 to 36 months at the time of questionnaire completion. Ethnic distribution is shown in Table 1.

Table 1

Ethnic Distribution of Participant Families

Ethnicity	Frequency/ Percentage
White	19 (44.2%)
Hispanic	12 (27.9%)
Combination	9 (20.9%)
Asian	1 (2.3%)
Black	1 (2.3%)
Other	1 (2.3%)
Total	43 (100%)

Diagnoses were distributed as shown in Table 2:

Table 2

Diagnoses of Children Reported On

Diagnosis	Frequency/ Percentage
Autism Spectrum Disorder (ASD)	17(39.5%)
Developmental Delay (DD)	16 (37.2%)
Sensory Processing Disorder (SPD)	5 (11.6%)
Developmental Coordination Disorder	1, 2.3%
DD/Deaf	2 (4.7%)
DD/SPD	2 (4.7%)
Total	43 (100%)

Of particular interest is that six of the 17 children diagnosed with ASD were sets of twins. Participating therapists confirmed a specific diagnosis was on file, however, independent confirmation of diagnosis was not obtained for this study.

The data were coded and grouped into descriptive categories. If there is no impairment in participation the total LPP score is 110 (five points for each of the 22 items). In consultation with the LPP creator the researcher coded the scores. Scores from 100-110 were described as unimpaired, scores of 80-99 were described as mildly impaired, scores of 60-79 as moderately impaired, and below 60 as significantly impaired. Scores on the LPP ranged from 43 to 99, with 44.2% reported mild impairment, 32.6% reported moderate impairment, and 23.3% reported severe impairment in participation. The average score was 70.37. There were no significant differences in the means of the various diagnostic categories for LPP scores.

Data were coded for the ITSP in keeping with the descriptive categories used by its developer. A code of zero indicated typical performance, a code of one indicated a difference from typical performance in the “less than others” category, and a code of two indicated difference in performance in the “more than others” category. Frequencies of scores for ITSP constructs are shown in tables three through six for the Quadrant Summary Scores of Low Registration, Sensation Seeking, Sensory Sensitivity, and Sensory Avoiding.

Table 3 shows frequencies of Low Registration scores on the ITSP.

Table 3

Low Registration Scores of Children as Reported by Parents

Code	Frequency	Percentage
0	5	11.6%
1	1	2.3%
2	37	86.1%
Total	43	100%

Table 4 shows frequencies of Sensation Seeking scores on the ITSP.

Table 4

Sensation Seeking Scores of Children as Reported by Parents

Code	Frequency	Percentage
0	24	55.8%
1	5	11.6%
2	14	32.6%
Total	43	100%

Table 5 shows frequencies of Sensory Sensitivity scores on the ITSP.

Table 5

Sensory Sensitivity Scores of Children as Reported by Parents

Code	Frequency	Percentage
0	14	32.6%
1	1	2.3%
2	28	65.1%
Total	43	100%

Table 6 shows the frequencies of Sensation Avoiding scores on the ITSP.

Table 6

Sensation Avoiding Scores of Children as Reported by Parents

Code	Frequency	Percentage
0	10	23.3%
1	1	2.3%
2	32	74.4%
Total	43	100%

Low Registration differences in performance were reported by 88% of respondents. This made it the most frequently reported difference in sensory processing. All but one of those reporting clinical differences fell into the “more than others” category.

CBCL 1.5-5 scores were coded in accordance with the categories of its scoring model, which are based on severity of symptoms reported. A code of zero indicated no clinical concerns about the behavior, a code of one indicated borderline (approaching levels of) clinical concern about the behavior, and a code of two indicated clinical concerns about the behavior. These frequencies of scores on the CBCL 1.5-5 Syndrome

Scales of Emotionally reactive, Anxious/Depressed, Somatic Complaints, Sleep Problems, Attention problems, and Aggressive Behavior are listed in Tables 7 to 12 below.

Table 7 shows frequencies of Emotionally Reactive Behavior scores on CBCL1.5-5.

Table 7

Frequency of Reports of Emotionally Reactive Behaviors in Children

Code	Frequency	Percentage
0	22	51.2%
1	11	25.6%
2	10	23.3%
Total	43	100%

Table 8 shows frequencies of Anxious/Depressed Behavior scores on CBCL 1.5-5.

Table 8

Frequency of Reports of Anxious/Depressed Behaviors in Children

Code	Frequency	Percentage
0	35	84.1%
1	5	11.6%
2	3	7.0%
Total	43	100%

Table 9 shows frequencies of Somatic Complaints scores on CBCL 1.5-5.

Table 9

Frequency of Reports of Somatic Complaints in Children

Code	Frequency	Percentage
0	34	79.1%
1	5	11.6%
2	4	9.3%
Total	43	100%

Table 10 shows frequencies of Withdrawn Behavior scores on CBCL 1.5-5.

Table 10

Frequency of Reports of Withdrawn Behavior in Children

Code	Frequency	Percentage
0	18	41.9%
1	4	9.3%
2	21	48.8%
Total	43	100%

Table 11 shows frequencies of Sleep Problems scores on CBCL 1.5-5.

Table 11

Frequency of Reports of Sleep Problems in Children

Code	Frequency	Percentage
0	35	81.4%
1	2	4.2%
2	6	14.0%
Total	43	100%

Table 12 shows frequencies of Attention Problems scores on CBCL 1.5-5.

Table 12

Frequency of Reports of Attention Problems in Children

Code	Frequency	Percentage
0	14	32.6%
1	5	11.6%
2	24	55.8%
Total	43	100%

Table 13 shows frequencies of Aggressive Behaviors scores on CBCL 1.5-5.

Table 13

Frequency of Reports Aggressive Behavior in Children

Code	Frequency	Percentage
0	29	67.4%
1	3	7.0%
2	11	25.6%
Total	43	100%

Attention problems and withdrawn behavior were the most frequently reported behavior problems and most often reported at levels that suggest need for clinical intervention for these behaviors

Diagnostic Comparison Between Children With ASD and Other Diagnoses

A preliminary review of the data suggested children with a diagnosis of ASD had significantly different responses on the CBCL 1.5-5 and the ITSP. Therefore the data were grouped for the children with ASD and children with a diagnosis other than ASD. ITSP data revealed that 16 out of 17 children with ASD scored in the Definite Difference “more than others” area of *Low Registration*, and 14 of the 17 scored in the Definite Difference “more than others” category of *Sensation Avoiding*. There were no other significant differences in ITSP scores between the children with ASD and those with a different diagnosis. On the CBCL 1.5-5 children with ASD scored significantly higher on the Withdrawn Behavior scale with a mean score of 8.5. A score of 8.5 is identified by the CBCL 1.5-5 as indicative of behavior, which might require clinical intervention. The children with other diagnoses had a mean score of 4.8 on the Withdrawn Behavior

scale, which is in the normal range. On the Attention Problems scale children with ASD had a mean score of 7, which is in the clinical range. Children with non-ASD diagnoses had a mean score of 5.4, which is in the normal range. Means on the remaining scales (Emotionally Reactive, Anxious/Depressed, Somatic Complaints, and Sleep Problems) were within one point on each other and all fell in the normal range for all diagnostic groups.

Correlation Analyses: Parent Participation, Sensory Processing and Maladaptive Behavior

To address the research questions of potential relationships between parent participation and child abnormal sensory processing and maladaptive behavior, correlation analyses were run on the data. Pearson Product Moment (r) Correlation is a commonly used measure to show relationships between constructs (Kielhofner, 2006). Pearson's r can be used when the variables are normally distributed and measured on interval scales (Kielhofner, 2006). The LPP, ITSP, and CBCL 1.5-5 meet these criteria. Additionally, correlation strength is measured on a scale of -1 to +1. Correlations that range from 0-0.4 are described as “weak”, those ranging from 0.4-0.8 are considered “moderate”, and those ≥ 0.8 are considered strong (Field, 2009). Three separate Pearson's r correlations were performed to compare:

- Total scores of LPP and raw quadrant scores of the ITSP constructs (Low Registration, Sensation Seeking, Sensory Sensitivity, and Sensation Avoiding);

- Total scores of LPP and raw syndrome scale scores of the CBCL 1.5-5 constructs (Emotionally Reactive, Anxious/Depressed, Somatic Complaints, Withdrawn Behavior, Sleep Problems, Attention Problems, and Aggressive Behavior).
- Raw quadrant scores of ITSP constructs (Low Registration, Sensation Seeking, Sensory Sensitivity, and Sensation Avoiding) and raw syndrome scores of the CBCL 1.5-5 constructs (Emotionally Reactive, Anxious/Depressed, Somatic Complaints, and Withdrawn Behavior, Sleep Problems, Attention Problems, and Aggressive Behavior).

Pearson r Correlation Analyses-LPP and ITSP

The null hypotheses postulated that there were no relationships between parent participation and sensory processing constructs (4 total). Correlations between the LPP and ITSP showed no significant relationships (null hypotheses are retained) between the constructs of parent participation and Low Registration, Sensation Seeking, Sensory Sensitivity or Sensation Avoiding.

Pearson r Correlation Analyses –LPP and CBCL 1.5-5

For the correlation between parent participation and CBCL 1.5-5 constructs the null hypotheses postulated that there were no relationships between behavior and parent participation constructs (7 total). Correlation analysis between the constructs of Anxious/Depressed Behavior and parent participation was $R = .388, p < .05$. This is a weak, negative relationship. Correlation analysis between the constructs of Sleep Behaviors and parent participation were $R = -.339, p < .05$, which is a weak, negative relationship. Correlation analysis between the constructs of Aggressive Behavior and

parent Participation were $R = -.359$, $p < .05$, which is a weak, negative relationship. The null hypotheses for these areas were rejected. The null hypotheses that there were no relationships between Emotionally Reactive, Somatic Complaints, Withdrawn Behavior, and Attention Problems were retained.

Pearson Correlation r Analyses ITSP and CBCL 1.5-5

Null hypotheses for the correlation between the sensory and behavior constructs were that there were no relationships between the ITSP constructs of Low Registration, Sensation Seeking, Sensory Sensitivity, and Sensation Avoiding and the CBCL 1.5-5 constructs of Emotionally Reactive, Anxious/Depressed, Somatic Complaints, Withdrawn Behavior, Sleep Problems, Attention Problems, and Aggressive Behavior (28 total). For ease of viewing, the correlations were grouped between the following areas:

- ITSP quadrants and *Internalizing Behavior* constructs of Emotionally Reactive, Anxious/Depressed, Somatic Complaints, and Withdrawn as shown in Tables 14 and 15 below,
- ITSP quadrants and *Externalizing Behavior constructs* of Attention Problems and Aggressive Behavior as shown in Tables 16 and 17 below, and,
- ITSP quadrants and Sleep Behavior as shown in Table 18 below.

Table 14

Correlations Between ITSP Low Registration and CBCL 1.5-5 Internalizing Behaviors

	Emotionally Reactive	Anxious/ Depressed	Somatic Complaints	Withdrawn
Low Registration	-.291	-.328*	-.301*	-.769**
Pearson r	.059	.032	.049	.000
Sig (2-tailed)	.43	.43	.43	.43
N				
Seeking				
Pearson r	-.301*	-.112	-.217	-.291
Sig (2-tailed)	.050	.475	.162	.058
N	43	43	43	43

Note: *Correlation is significant at the 0.05 level (2-tailed); **Correlation is significant at the .01 level (2-tailed)

Table 15

Correlations Between ITSP Sensory Sensitivity and Sensation avoiding and CBCL 1.5-5 Internalizing Constructs

	Emotionally Reactive	Anxious/ Depressed	Somatic Complaints	Withdrawn
Sensitivity				
Pearson r	-.752**	-.656**	-.642**	-.268
Sig (2-tailed)	.000	.000	.000	.082
N	43	43	43	43
Avoiding				
Pearson r	-.724**	-.629**	-.596**	-.476**
Sig (2-tailed)	.000	.000	.002	.002
N	43	43	43	43

Note: *Correlation is significant at the 0.05 level (2-tailed); **Correlation is significant at the .01 level (2-tailed)

Table 16

Correlations Between ITSP Low registration and Sensation Seeking and CBCL 1.5-5 Externalizing Behavior

	Attention Problems	Aggressive Behavior
Low Registration		
Pearson r	-.501**	.413**
Sig (2-tailed)	.001	.006
N	43	43
Seeking		
Pearson r	-.518**	-.285
Sig (2-tailed)	.000	.064
N	43	43

Note: *Correlation is significant at the 0.05 level (2-tailed); **Correlation is significant at the .01level (2-tailed)

Table 17

Correlations Between ITSP Sensitivity and Avoiding and CBCL 1.5-5 Externalizing behaviors

	Attention Problems	Aggressive Behavior
Sensitivity		
Pearson r	-.263	-.583**
Sig (2-tailed)	.088	.000
N	43	43
Avoiding		
Pearson r	-.455**	-.563**
Sig (2-tailed)	.002	.000
N	43	43

Note: *Correlation is significant at the 0.05 level (2-tailed); **Correlation is significant at the .01level (2-tailed)

Table 18

Correlations Between ITSP Quadrants and CBCL 1.5-5 Sleep Problems

	Sleep Problems
Low Registration	
Pearson r	-.213
Sig (2-tailed)	.170
N	43
Seeking	
Pearson r	-.224
Sig (2-tailed)	.148
N	43
Sensitivity	
Pearson r	-.328*
Sig (2-tailed)	.011
N	43
Avoiding	
Pearson r	-.353*
Sig (2-tailed)	.020
N	43

Note: *Correlation is significant at the 0.05 level (2-tailed); **Correlation is significant at the .01 level (2-tailed)

Multiple Regression Analyses

Multiple regression analysis was then used to determine predictability of the effect of the independent variables of the behavior constructs of internalizing versus externalizing on parent participation. Field (2009) states that regression analysis allows for the prediction of outcomes “based on values of predictive variables” (p.198). Use of multiple regression analyses requires that certain assumptions be satisfied. The first two assumptions are that the dependent variable and independent variables (more than one) be measured on continuous scales. The LPP, ITSP, and CBCL 1.5-5 meet these

assumptions. Researchers must check for violation of the no multi-collinearity assumption, or that variables are not too closely related to one another (Field, 2009). Pearson *r* correlation coefficients, the tolerance level, and variable inflation factor (VIF) levels between the predictive variables (Field, 2009) were reviewed to validate this assumption. To determine the statistical significance and relative importance of each independent variable in the regression analysis the unstandardized and standardized beta coefficients were examined. Data from this study revealed no correlation between parent participation (LPP) and the ITSP constructs of Low Registration, Sensation Seeking, Sensory Sensitivity, and Sensation Avoiding, therefore regression analysis between these constructs was not appropriate since the assumptions were not met.

Regression Analysis Between the Constructs of LPP and CBCL 1.5-5

The postulated null hypotheses for regression analyses were that there are no predictive relationships between parent participation and Internalizing Behaviors (Emotionally Reactive, Anxious/Depressed, Somatic Complaints, and Withdrawn Behaviors.) and no predictive relationships between parent participation and Externalizing Behaviors (Attention Problems and Aggressive Behavior). The results of regression analysis between CBCL 1.5-5 Internalizing Behavior constructs of Emotionally Reactive, Anxious/Depressed, and Somatic Complaints are listed in Table 19 below.

Table 19

Multiple Regression Analysis for Variables Predicting Parent Participation

	b	SE b	B	t	Significance
Constant	83.993	6.602		12.722	.000
Emotionally Reactive	1.202	1.075	.313	1.118	.271
Anxious/Depressed	-2.555	1.481	-.480	-1.724	.093
Somatic Complaints	-.113	1.081	-.022	-.105	.917
Withdrawn	1.058	.765	.252	1.383	.175
Sleep problems	-.434	.831	-.103	-.522	.605
Attention Problems	-1.103	1.226	-.179	-.900	.374
Aggressive Behavior	-.383	.380	-.239	-1.008	.320

$R^2 = .117$, $F(2,40) = 15.872$, $p = >.05$. ($N=43$).

The data show no significant predictive relationships between behavior constructs and parent participation. The null hypotheses for predictive qualities between behavior constructs and parent participation are retained.

Regression analysis between the constructs of ITSP and CBCL 1.5-5.

The postulated null hypotheses for regression analysis were that there were no predictive relationships between ITSP constructs of Low Registration, Sensation Seeking, Sensory Sensitivity, and Sensation Avoiding and CBCL 1.5-5 constructs of internalizing behaviors (Emotionally Reactive, Anxious/Depressed, Somatic Complaints, and Withdrawn Behaviors). The results of the regression analysis between

the ITSP Quadrant Scores of Low Registration, Sensation Seeking, Sensory Sensitivity, and Sensation Avoiding with CBCL 1.5-5 constructs of Internalizing Behaviors are listed in Table 20.

Table 20

Multiple Regression Analysis for variables predicting Internalizing Behaviors (N=43)

	b	SE b	β	t	Significance
Constant	57.840	5.273		10.968	.000
Low Registration	-.358	.131	-.301	-2.742	.009
Sensation Seeking	.116	.119	.102	.975	.336
Sensory Sensitivity	-.445	.196	-.401	-2.270	.029
Sensation Avoiding	-.346	.202	-.329	-1.175	.095

$R^2 = .676$, $F(4,38) = 6.337$, $p = >.05$

These data show that there is a predictive relationship between Low Registration characteristics and Internalizing Behaviors. They further show a predictive relationship between Sensory Sensitivity characteristics and Internalizing Behaviors because their p -values are less .05. The null hypotheses for predictive relationships between Low Registration and Sensory Sensitivity and Internalizing Behaviors are rejected. The null hypotheses for predictive relationships between Sensation Avoiding and Sensation Seeking and Internalizing Behaviors are retained.

The final set of postulated null hypotheses for regression analysis were that there were no predictive relationships between ITSP constructs of Low Registration, Sensation Seeking, Sensory Sensitivity, and Sensation Avoiding and CBCL 1.5-5 constructs of Externalizing Behavior (Attention Problems and Aggressive Behaviors). The results of the regression analysis between the ITSP Quadrant Scores of Low Registration, Sensation Seeking, Sensory Sensitivity, and Sensation Avoiding with CBCL 1.5-5 constructs of Externalizing Behaviors are listed in Table 21.

Table 21

Multiple Regression Analysis for Variables Predicting Externalizing Behaviors (N=43)

	b	SE b	β	T	Significance
Constant	59.952	8.010		7.485	.000
Low Registration	-.279	.198	-.212	-.990	.329
Sensation Seeking	-.179	.181	-.141	-1.039	.305
Sensory Sensitivity	-.309	.297	-.252	-.738	.465
Sensation Avoiding	-.226	.306	-.194	-1.408	.167

$R^2 = .390$, $F(4,38) = 6.072$, $p > .05$

The analysis shows that Low Registration, Sensation Seeking, Sensory Sensitivity, and Sensation Avoiding did not significantly predict Externalizing Behaviors. The null hypotheses for ITSP constructs and Externalizing Behaviors are retained.

CHAPTER V

DISCUSSION

Participation in occupations is central to health (OTPF, 2013; WHO, 2002) yet there is limited research into the effects of young children's maladaptive behavior and abnormal sensory processing on their parent's participation. The OTPF (2013) states, and ECI federal legislation IDEA-Part C (Pub. L.108-446, 20 U.S.C. 1400 et seq.) mandates that family and caregivers' participation be central to any treatment of the child (OSEP, 2008). This study sought to explore factors that might be related to parental participation while raising a young child with special needs. This study looked at relationships between parent participation and abnormal sensory processing; parental participation and maladaptive behaviors; and between maladaptive behaviors and abnormal sensory processing in young children. These relationships were explored through Pearson *r* correlation and multiple regression analyses. Pearson R correlations are used to establish that a relationship exists (Field, 2009). Regression analysis can then be used to determine if there is a predictive nature of that relationship (Field, 2009). Forty-three parents and grandparents completed three standardized, parent questionnaires identifying their abilities to participate in various life occupations (LPP, Fingerhut, 2005), their child's sensory processing skills (ITSP, Dunn & Daniels, 2002), and their child's behaviors (CBCL 1.5-5, Achenbach & Rescorla, 2000) that provided data to explore these relationships.

The first research question was: Do levels of sensory processing as measured by the ITSP (Dunn & Daniels) correlate with parent participation as measured by Life

Participation of Parents (Fingerhut)? This question was answered negatively with Pearson r Correlation tests that showed no significant relationships between the ITSP constructs of Low Registration, Sensation Seeking, Sensory Sensitivity, and Sensation Avoiding. Since there were no direct relationships regression analyses could not be completed between these constructs. Although no significant relationships were found, these results adds preliminary data to understanding parent participation while raising a child with special needs, a topic which, to date, is limited to qualitative information. .

The second research question was: Do levels of maladaptive behavior, as measured by the CBCL 1.5-5 (Achenbach & Rescorla), correlate with levels of parent participation as measured by the LPP (Fingerhut, 2005)? This question was answered affirmatively with Pearson r Correlation tests that showed weak, inverse relationships between Anxious/Depressed Behavior, Sleep Behavior, and Aggressive Behaviors and parent participation. Regression analyses however revealed no significant predictive nature to the relationships between these constructs. This supports the literature that shows parents experience increased levels of stress and anxiety when they had difficulty engaging in personal or family activities due to their child's aggressive and unpredictable behaviors (Montes & Halterman, 2008). Furthermore, the literature indicates life disruption around unanticipated events evokes sensory defensiveness in children, which contributes to family stress and anxiety as found in this study (DeGrace, 2004; Schaaf, et al., 2011)

The third research question was: Does the pattern of sensory presentations as measured by the ITSP (Dunn & Daniels, 2002) correlate with maladaptive behaviors as

measured by CBCL (Achenbach & Rescorla, 2000)? This was answered affirmatively with Pearson r Correlation tests that showed moderate negative relationships between the ITSP constructs of Sensory Sensitivity and Sensation Avoiding and the CBCL 1.5-5 (Achenbach & Rescorla) combined construct of *Internalizing Behaviors* (Emotionally Reactive, Anxious/Depressed, Somatic Complaints, and Withdrawn scores combined). This supports the research and models of Baker, Lane, Angley & Young (2008), Ben-Sasson et al. (2008), and Dunn (1997). However Sensory Sensitivity and Sensation Avoidance also correlated with the *Externalizing Behavior* of aggression in this study, which is supported in other literature such as Ben-Sasson, Carter and Briggs-Gowan (2009) and Tseng, Fu, Cermak, Lu, & Shieh, (2011). Many parents in this study described their children as having Definite Differences “more than others” in multiple areas of the ITSP such as displaying characteristics of both extreme Sensation Seeking and extreme Sensation Avoiding. This supports the literature related to the complex nature of sensory processing in children with ASD (Kientz & Dunn, 1997; Rogers, Hepburn, S., & Wehner, 2003; Watling, Dietz & White, 2001). Regression analysis further revealed a predictive nature between the constructs of Low Registration and Sensory Sensitivity constructs on the ITSP and Internalizing Behaviors on the CBCL 1.5-5. This adds evidence to the theory that maladaptive behaviors are correlated with and may result from sensory processing experiences (Ayres, 1972; Ayres, 1979; Baker, Lane, Angley & Young, 2008; Baranak, 1999; Dunn, Myles & Orr, 2002).

In addition, frequency data from this study added depth to the existing information in each area and supported the literature. CBCL 1.5-5 (Achenbach &

Rescorla) revealed an overwhelming majority of children with clinically significant Withdrawal Behavior. Behaviors in this scale include “acts too young”, “avoids eye contact”, “refuses active games”, and “unresponsive to affection,” among others. Parents described Internalizing Behaviors such as these as producing the most stress and as the source of parent-child problems in studies by Eisenhower, Baker and Blacher (2005) and Davis and Carter (2008) respectively. This could explain why Withdrawal was so extensively identified in this study of participation. Withdrawal was the most commonly described behavior problem in young children with ASD in a study by Hartley, Sikora & McCoy (2008) and with DD (Baker, Blacher, Crnic & Edelbrock, 2002), which is supported by the results of the current study.

Children With ASD versus Non-ASD Diagnoses

The children with ASD in this study had a high presentation of Low Registration (or hypo-arousal). All the children with ASD (17/17) in this study scored in the Definite Difference “more than others” area of Low Registration. Moreover, nearly all of those (15/17) scored in the Definite Difference “more than others” category of Sensation Avoiding. No child with ASD had a completely, or even mostly, “typical” sensory response profile (at least two of four quadrant scores in clinically significant levels of either “Probable Difference” or “Definite Difference”). All of these findings support the work of others that found predominantly hypo-aroused presentations and clinically significant scores in many sensory areas simultaneously in children with ASD (Baranek, et al., 2006; Ben-Sasson et al., 2009, Rogers, Hepburn & Wehner, 2003; Rogers & Ozonoff, 2005; Tomchek & Dunn, 2007).

Many children with DD, SPD, or combinations *not* including ASD in this study also showed significant sensory processing differences. Moreover, they scored very similarly to the children with ASD in the areas of Low Registration and Sensation Avoiding. This adds to the limited sensory data on children with general developmental delays (Boyd, et al., 2010), but contrasts findings of others (Baranek et al., 2006; Tomcheck & Dunn, 2007).

The behaviors of children with a diagnosis of ASD were similar to non-ASD diagnosed children. There were no significant differences (within one to two points) on the constructs of Emotional Reactive, Anxious/Depressed, Somatic Complaints, Sleep, Attention, and Aggression. The category means showed sub-clinical (not suggestive of a need for clinical intervention) levels overall. However, the children with ASD had a 77% higher mean level of Withdrawal compared to those without ASD. These results support the research of numerous others (Achenbach & Rescorla, 2002; Ashburner, Ziviano & Rodger, 2008; Baker, Lane, Angley & Young, 2008; Hartley, Sikora & McCoy, 2008; Tomanik, Harris & Hawkins, 2004) and provide further support for the first criterion in DSM-V's diagnostic category 299.0 of Autism Spectrum Disorder, which are deficits in social interaction (APA, 2013). It is worth noting that that 37% of participants in this study of children less than 36 months of age already have a medical diagnosis of ASD whereas the nationwide average age of diagnosis is four years old (CDC.org).

Limitations

The primary limitation of this study is its lack of power. The recruitment of parents of young children proved difficult for myriad reasons including the parent's busy schedules, difficulty keeping the child occupied while they completed the forms, not having enough time due to household and childcare demands, and other reasons related to life with small children. Recruitment and participation was also dependent on a commitment from the treating therapist. Therapists' time limitations were often a factor in how thoroughly they could process the questionnaires with parents. The majority of parents required more than one hour to complete the forms and needed clarification on both ITSP (Dunn & Daniels, 2002) and CBCL 1.5-5 (Achenbach & Rescorla, 2000) items, which could explain why some neglected to complete them fully. The addition of more participants could lead to stronger correlations and perhaps predictive relationships between the constructs of behavior and sensory processing and parent participation.

The time at which the study procedures were introduced was another possible limitation. Many of the children had been in treatment for sensory and behavioral issues for several weeks to several months. Those completing the forms at the beginning of this process, prior to any intervention, may have scored their child's performance differently than those who have been in treatment for some time. Only "time since diagnosis" was recorded on the demographic sheet, therefore this information was not obtained.

The subtleties in the scoring of ITSP (Dunn & Daniels, 2002) proved difficult to capture in SPSS analysis. The ITSP (Dunn & Daniels) yields data that include "Probable Difference" and "Definite Difference" scores at both the *high* and *low* points of the scale

with severities (of difference from typical performance) that vary according to the child's age. Because of the low numbers of children in this study they could not be grouped further into these homogenous categories for analysis. Grouping them in this manner could have clarified some of the subtle differences in sensory processing and their impact on parent participation. ITSP Section Summaries scores (auditory, visual, touch, vestibular, and oral sensory) were not used in this study. Section summary information would have added more specific information about the children's sensory performance.

Although instructed to use the LPP in an interview format either during or after administration, therapists were not consistent in the administration of the LPP (Fingerhut, 2005). Some therapists asked the questions, clarifying meaning when needed, and wrote the answers. Others allowed parents to keep the (coded) form at home and work on them for several weeks then followed this with only brief conversations. These strategies were allowed to reduce the imposition on the therapist's and family's time and involvement.

Inconsistency in administration might have had an effect on parent responses. It is noted that there were some discrepancies between the families' reports of their child's sensory processing and behavior concerns and answers on the LPP (Fingerhut, 2005). Therapists communicated on a few occasions that they did not feel the parent had answered questionnaire items accurately. One example is a parent who reported several sleep problems on the CBCL 1.5-5 (Achenbach & Rescorla, 2000), noting that their child wakes up multiple times throughout the night, rarely sleeps for more than 20 minutes at time, and causes the whole family to be sleep-deprived, but did not endorse disruption to their own sleep on the LPP Item 21 (Fingerhut). These apparent contradictions could not

be explored due to time constraints, but offer insight into how to most effectively use the LPP (Fingerhut).

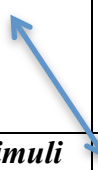
Many parents made no comments on the LPP (Fingerhut, 2005). More detailed responses could have enhanced understanding of participation limitations that could have yielded more accurate data for this study. The incorporation of qualitative data might have added specific information as to which occupations (ADLs, IADLS etc.) are most affected by raising a child with special needs.

Clinical Applications

Dunn (1997) notes that researchers can only observe behavior as evidence of what the child is experiencing. Children do not possess the language or cognitive skills to describe sensory neurological responses. Children's behavior shows the observer how the child is reacting to their individual threshold for sensory input (Dunn). Application of Dunn's Model of Sensory Processing to the data in this study shows the following continuums of neurological threshold and behavioral responses to these:

Dunn's Model of Sensory Processing

Neurological Threshold Continuum	Behavioral response Continuum Responds in ACCORDANCE with threshold	Responds to COUNTERACT the threshold
HIGH (Habituation)	<i>Poor Registration</i>	<i>Sensation Seeking</i>
LOW (Sensitization)	<i>Sensitivity to Stimuli</i>	<i>Sensation Avoiding</i>



Model taken from: Dunn (1997). The Impact of sensory processing abilities on the daily lives of young children and their families: A conceptual model. *Infants and Young Children*, 9 (4): 23-25.

The majority of children in this study were described as having Low Registration (88%) and as being Sensation Avoiding (75%). Dunn describes children with these issues as being “withdrawn and difficult to engage” (p. 31). This would seem to correspond with the prevalence of CBCL 1.5-5 (Achenbach & Rescorla, 2000) scores in the Withdrawn (>59%) and Attention (>66%) problem areas. In this sample of children, those who presented as withdrawn and inattentive (observable behaviors) were also noted to have characteristics of Low Registration and a need for more, or enhanced qualities of an input to recognize and respond to it. These children were likely to engage in a strategy of sensation avoidance to maintain this neurological state, thereby maintaining the cycle between habituation and sensitization as described in Dunn’s (1997) model above.

This study found predictive relationships that can be considered in clinical settings. A predictive relationship between inattentive, withdrawn children and Low Registration and Sensation Avoidance patterns means therapists can anticipate a need to increase the intensity, frequency, or kind of input offered to these children so that they can more effectively participate in development-enhancing experiences. Therapists can modify the sensory aspects of both home and social environments to meet the particular threshold and motivational needs of a child. Likewise therapists can teach parents to implement these strategies in the home and community environments to enhance participation in developmental opportunities as is suggested by Dunst et al. (2001).

The frequency data from this study show many observable sensory characteristics and behaviors that can be valuable in clinical settings. Behaviors can provide information to physicians and others to develop the diagnostic picture of a child with ASD, Attention Deficit Hyperactivity Disorder, and Anxiety Disorders among others. This is one of the stated purposes of the CBCL 1.5-5 (Achenbach & Rescorla, 2002). ITSP was designed to help clinicians identify sensory processing patterns that might interfere with a child's participation, which is critical to intervention planning (Dunn & Daniels, 2002). ECI therapists in particular intervene at a very early point in the child's life therefore they can help parents recognize their child's atypical behavioral and sensory responses and how these may be preventing participation. If parents recognize and feel equipped to manage these differences it could better prepare them for potential diagnoses and help them anticipate needs the child may have to more effectively engage in occupations.

The various and often extensive reports of sensory and behavioral concerns parents reported in their child confirm much of what this researcher sees in the clinical setting. Administering occupational therapists also reported that the families expressed concerns about abnormal sensory processing and maladaptive behavior and actively sought help with these issues. Sensory and behavioral issues in young children can be complex as seen in the results of this study. Their complexity and variability make intervention difficult for therapists and families. The data from this study confirms these clinical experiences.

Future Directions

A replication of this study with higher participant numbers would contribute to the knowledge gained from this study and add to the power and generalizability of the results. A larger study would also allow for more specific characterization of behavior and sensory constructs that impact parent participation.

The use of the other portions of each tool would also enhance future studies. The use of ITSP Section Summaries (Auditory Processing, Visual Processing, Tactile Processing, Vestibular Processing, and Oral-Sensory Processing) would add further detail to a child's sensory performance. The use of the CBCL 1.5-5 Syndrome Scales would add a diagnostic dimension. The use of the comments sections of the LPP would add a qualitative aspect to the overall interpretation of impact of maladaptive behaviors and sensory processing abnormalities on parent participation.

A study of LPP's metrics with a control group of typically developing toddlers could increase understanding of typical parent participation during this phase of life. It

could help define existing differences between parenting typically developing children versus those with special needs. It may be that raising infants and toddlers leads to natural disruption to parental participation and the reported levels of impairment in this study would have been found regardless of the child's developmental status or reported maladaptive behaviors and sensory abnormalities.

The frequency data from this study also suggest directions for future studies. There was widespread endorsement of Low Registration on the ITSP (Dunn & Daniels, 2002) in this sample of children, however, no correlation was found with this construct and parent participation. This finding warrants further exploration as to its prevalence among children receiving services from occupational therapists. Since sensory-based treatment is the most frequently requested in pediatric occupational therapy (Watling, Deitz, Kanny & McLaughlin, 1999), it would be valuable to explore if behaviors measured on this scale, such as having to speak loudly or touch the child to get his attention, are ones that present participation barriers for parents, children individually and as a family unit. Outcomes studies that include specific interventions for Low Registration and Withdrawal, with use of the ITSP (Dunn & Daniel, 2002) and CBCL 1.5-5 (Achenbach & Rescorla, 2000) as measurement tools, would also be appropriate given the prevalence of these reported characteristics. A secondary goal of this study was to identify a more homogenous group of children for future sensory intervention effectiveness studies.

From the data collected in this study a specific outcome study with children with Low Registration and Withdrawal qualities would be appropriate. This could be done

with initial administration of the LPP (Fingerhut, 2005), ITSP (Dunn & Daniels, 2002) and the CBCL 1.5-5 (Achenbach & Rescorla, 2000). This could be followed with specific interventions to address behaviors associated with the Low Registration/Withdrawal presentation (i.e. not responding when their name is called, avoiding certain environments and inputs) using a fidelity measure to train and insure consistency of its usage among therapists. The intervention could be provided for a prescribed amount of time and be followed with re-administration of the LPP (Fingerhut, 2005), ITSP (Dunn & Daniels, 2002) and the CBCL 1.5-5 (Achenbach & Rescorla, 2000). This would add to the limited data on frequency and intensity (dosage) of treatment needed to have an impact on sensory processing and behavior of young children. It would also yield data on how changes in the child impact parent participation, the ultimate purpose of the LPP (Fingerhut, 2005; Fingerhut, 2009).

A longitudinal study that follows children with DD, SPD and DCD diagnoses over time using CBCL 1.5 and ITSP could add to the existing literature on the identification of ASD related characteristics in young children prior to diagnosis (Baranak, 1999; Tomchek & Dunn, 2007; Werner, Dawson, Osterling & Dinno, 2000). Many parent reports indicated that their children with non-ASD diagnoses displayed sensory and behavioral characteristics that were very similar to those diagnosed with ASD. While ITSP is not meant as a diagnostic tool, it's possible that studies with much greater participant numbers may provide valuable information to the diagnostic decision-making process. This is highly relevant now that the APA has included sensory processing differences in its diagnostic criteria for ASD (APA, 2013). Furthermore, it

may identify unique sensory presentations in different diagnostic groups, which can enhance clinical understanding of the disorders and ultimately enhance intervention.

Summary

This study sought to explore the relationships between: parent participation and abnormal sensory processing, parent participation and maladaptive behaviors, and sensory processing abnormalities and maladaptive behaviors. The study did this through frequency data, Pearson *r* Correlation analyses, and multiple regression analyses. Abnormal sensory processing did not impact parent participation in this sample, although parents reported widespread abnormal sensory processing. Anxious/Depressed Behavior, Sleep Behavior, and Aggressive Behaviors showed weak inverse relationships with parent participation, whereas Emotionally Reactive, Somatic Complaints, Withdrawn Behavior and Attention Problems were not found to affect parent participation. Maladaptive behaviors and abnormal sensory processing showed numerous inverse relationships of various strengths; however the strongest were between the sensory construct of Low Registration and the behavioral construct of Withdrawal, and the sensory construct of Sensory Sensitivity and the behavioral constructs of Emotionally Reactive and Anxious/Depressed Behavior. The data from this study supports much of the existing literature on abnormal sensory processing and maladaptive behavior, but also adds to the limited literature on these issues in young children with various developmental delays and on their impact to parent participation.

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APPENDIX A

The Life Participation For Parents ® 2005; English Version. Patricia Fingerhut, OTR,

PhD

Life Participation for Parents (LPP) ® (2005)

Background Literature	Family-centered practice goes beyond child related goals to incorporate changing the quality of life for the whole family (Rosenbaum, King, Law, King, & Evans, 1998). Families are interdependent and intervention with the child can have a significant impact on life participation for the entire family, especially the parents. Raising a child with special needs can influence a parent's time usage, health, and choice of activities (Crowe, 1993; Jones & Passey, 2005; Kahaneck, Burroughs, Wright, Lemonskyk & Daeragh, 2010; & Schauf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). In order to provide best-practice family-centered intervention therapists need to understand individual barriers to life participation for the child, parents, and other family members (Hinojosa, Sprout, Minkhetwit & Anderson, 2002; Roberts & Lawton, 2001; Rosenbaum et. al, 1998).
Source	Patricia E. Fingerhut, OTR, PhD. 301 University Boulevard Galveston, Texas, 77555-1142 pefinger@utmb.edu
References	Fingerhut, P.E. (2013) Life Participation for Parents: A tool for family-centered occupational therapy, <i>American Journal of Occupational Therapy</i> , 67(1), 37-44. Fingerhut, P.E. (2009). Measuring Outcomes of Family-Centered Intervention: Development of the Life Participation for Parents (LPP). <i>Physical & Occupational Therapy in Pediatrics</i> , 29(2), 113-128.
Purpose	The LPP was developed to enhance family-centered practice by providing a self-report questionnaire to measure satisfaction with the efficiency and effectiveness of parental life participation while raising a child with special needs.
Type of Client	The LPP is appropriate for any primary caregiver of a child with special needs.
Clinical Utility	The LPP consists of 23 items related to activities / occupations engaged in by primary caregivers that may be influenced by the role of raising a child with special needs. Questions relate to the parent/caregiver's satisfaction with the effectiveness (quality of performance) and efficiency (time spent) of participation in activities / occupations. Parents/caregivers complete the questionnaire using a 5-point Likert scale. There is also space for qualitative comments to provide more information to the therapist for focused follow-up. It takes approximately 10 minutes for the client to complete the LPP and less than 10 minutes for the therapist to score.
Format	
Procedures	
Completion time	
Reliability	n = 162, $\alpha = .90$ (Fingerhut, 2013) n = 17, $r = .89$ (Fingerhut, 2013)
Internal Consistency	
Test-retest	

Validity Goodwin & Leach, 2003 test content	Content of the questionnaire items was established through literature review and review by therapist and parent stakeholders (Fingerhut, 2009)
response processes	Interviews with parents and therapists established that the items/questions were understood, were relevant to the construct being measured, and captured a range of responses providing evidence of response processes (Fingerhut, 2009)
internal structure	A principal component analysis resulted in a 2- factor model accounting for 43.81% of the variance. These factors represented the satisfaction with efficiency and satisfaction with effectiveness consistent with the occupational adaptation frame of reference used in constructing the questionnaire (Fingerhut, 2013)
relations to other variables	The LPP correlated moderately with the Parenting Stress Index – Short Form (Abidin, 1986) ($n = 37, r = .54$). Variables of child's diagnoses, age, or time in therapy did not predict parental responses (Fingerhut, 2013)
consequences of testing	More research using the LPP in practice is needed to establish consequences.
Sensitivity to Change	Test-retest reliability has demonstrated that responses are stable over the short term. Further research in a pretest – intervention – posttest format is needed to establish if the LPP is sufficiently sensitive to measure outcomes.
Administration Procedure	The LPP can be given to a parent/caregiver to be completed during a treatment session, in the waiting room, or to be returned at a future time. It should be explained to the parent/caregiver that the questions relate to the parent/caregiver's life participation and not the child's, and that the information is to assist in developing family-centered intervention.
Scoring Procedure	A lower score indicates more participation issues. Questions are worded both positively and negatively. For this reason questions 2,4,6,8,10,11, & 12 need to be reverse scored. (ie. The chosen Likert score is subtracted from 6 (6-x) in these questions to give the score that will be added into the total.) Therapists can use the scores to assess relative concerns for the parents and the qualitative comments to develop further dialogue for designing family-centered intervention.
Background References	<p>Abidin, R.R. (1988). <i>Parenting Stress Index</i>. Charlottesville, VA: Pediatric Psychology Press.</p> <p>Crowe, T.K. (1993). Time use of mothers with young children: The impact of a child's disability. <i>Developmental Medicine and Child Neurology</i>, 35, 621-630.</p> <p>Goodwin, L.D. & Leach, N.L. (2003). The meaning of validity in the <i>New Standards for Educational and Psychological Testing: Implications for measurement issues. Measurement and Evaluation in counseling and Development</i>, 36, 181-191.</p> <p>Ikagawa, J., Spence, C., Maekhtreit, S., & Anderson, J. (2002). Shifts in parent-therapist partnerships: Twelve years of change. <i>American Journal of Occupational Therapy</i>, 56(5), 556-563.</p> <p>Jones, J. & Panay, J. (2005). Family adaptation, coping and resources: parents of children with developmental disabilities and behavior problems. <i>Journal of Developmental Disabilities</i>, 11(1), 31-46.</p> <p>Kuhmbeck, H.M., Burroughs, T., Wright, J., Lovanczyk, T., & Derrigh, A. (2010). A qualitative study of coping in mothers of children with an autism spectrum disorder. <i>Physical & Occupational Therapy in Pediatrics</i>, 30(4), 340-350.</p> <p>Roberts, K. & Lawson, D. (2001). Acknowledging the extra care parents give their disabled children. <i>Child Care, Health & Development</i>, 27(4), 307-319.</p> <p>Rosenbaum P., King S., Law M., King, G., & Evans, J. (1998). Family-centered service: A conceptual framework and research review. <i>Physical and Occupational Therapy in Pediatrics</i>, 18(1), 1-20.</p> <p>Schaaf, R., Toth-Cohen, S., Johnson, S., Outten, G. & Bowerides, T. (2011). The everyday routines of families of children with autism. <i>Autism</i>, 15(3), 373-380.</p>

Life Participation for Parents (LPP) ® (2005)

Patricia E. Fingerhut, OTR, PhD.

Parent's Name _____

Child's Name _____

Quality therapy needs to be family-centered. Raising children with special needs affects all family members. This questionnaire addresses many activities of a parent/caregiver that may be affected by raising a child with special needs.

Instructions: Read the questions and think how this aspect of your life is affected by raising a child with special needs. Circle the response that most closely describes how you feel about the statement. Explain how these activities are difficult on the lines labeled comments below. If the question does not apply to you circle not applicable.

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
1	2	3	4	5	6

1. I spend more of my time caring for my child's physical and personal hygiene needs than I would like. (e.g. feeding, bathing, toileting, dressing, safety, moving them around, etc.)

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
Comments: _____					

2. I am able to manage my child's physical and personal hygiene needs.

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
Comments: _____					

3. I spend more of my parenting time doing things a teacher/therapist would do with my child than I would like. (e.g. homework, therapy home programs etc.)

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
Comments: _____					

4. I feel I do a good job when I do the things a teacher/therapist might do for my child.

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
Comments: _____					

5. My child's need for emotional support is wearing me out. (e.g. not able to entertain themselves, upset easily, cannot manage change in routine etc.)

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
Comments: _____					

6. I am able to meet my child's emotional needs.

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
Comments: _____					

7. I spend more time arranging services for my child than I would like. (e.g. appointments with health professionals, school services etc.)

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
Comments: _____					

8. I am good at getting services for my child.

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
Comments: _____					

9. I spend more of my time arranging and providing social activities for my child, than I would like. (e.g. things to do, people to play with etc.)

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
Comments: _____					

10. I am good at providing for my child's social activities.

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
Comments: _____					

11. I am able to manage household chores while caring for my child. (e.g. paying bills, cleaning, making meals, doing laundry etc.)

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
Comments: _____					

12. I am able to effectively do errands with my child. (e.g. shopping, banking, deliveries)

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
Comments: _____					

13. Having a child with special needs has interfered with my ability to hold a job or pursue education.

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
Comments: _____					

14. Financial issues related to my child's special needs are a source of stress for our family.

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
Comments: _____					

15. Having a child with special needs has restricted my ability to spend time with my friends and family as often as I would like to.

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
Comments: _____					

16. Spending time with my friends and family with my child present is stressful.

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
Comments: _____					

17. Having a child with special needs restricts the time I would like to spend with my spouse / significant other.

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
Comments: _____					

18. Having a child with special needs restricts the time I would like to spend with my other children.

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-------------------------	----------	-------------------	----------------

Comments: _____

19. Having a child with special needs affects my ability to be involved in community activities as often as I would like. (e.g. religious services, charitable organizations, political or community organizations)

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-------------------------	----------	-------------------	----------------

Comments: _____

20. Having a child with special needs has affected my health.

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-------------------------	----------	-------------------	----------------

Comments: _____

21. Having a child with special needs has affected my sleep.

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-------------------------	----------	-------------------	----------------

Comments: _____

22. Having a child with special needs affects my opportunities to engage in personal activities. (e.g. hobbies, sports, leisure activities)

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-------------------------	----------	-------------------	----------------

Comments: _____

23. Thinking back on a typical day, are there other activities that you would like to participate in? How are these affected by having a child with special needs?

Comments: _____

APPENDIX B

Participación de Vida Para Los Padres ® 2005

Patricia Fingerhut, OTR, PhD

**Participación de Vida para los Padres (LPP) ® (2005) Patricia E.
Fingerhut, OTR, PhD**

Nombre de padre: _____ Nombre de hijo: _____

Terapia de calidad debe estar centrada en la familia. Criar hijos con necesidades especiales, afecta a todos los miembros de la familia. Este cuestionario se refiere a muchas actividades de un padre/cuidador que podrían verse afectadas por criar a un niño con necesidades especiales.

Instrucciones: Leer las preguntas y pensar cómo este aspecto de su vida se ve afectada por criar a un niño con necesidades especiales. Circulo la respuesta que más cerca se describe cómo te sientes acerca de la declaración. Explicar cómo estas actividades son difíciles en las siguientes líneas comentarios a continuación. Si la pregunta no se aplica a usted, circulo «no aplicable.»

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica
1	2	3	4	5	6

1. Paso más de mi tiempo atendiendo las necesidades de higiene físicas y personales de mi hijo que me gustaría. (e.g. alimentación, bañarse, ir al baño, vestir, seguridad, movimientos, etc.)

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica

Comentarios: _____

2. Puedo manejar las necesidades de la higiene físicas y personales de mi hijo.

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica

Comentarios: _____

3. Paso más tiempo haciendo las cosas que un maestro o terapeuta podría hacer con mi hijo que me gustaría. (e.g. tareas, inicio programas de terapia en casa, etc.)

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica

Comentarios: _____

4. Creo que hacer un buen trabajo cuando hago las cosas que un maestro o terapeuta pudieran hacer por mi hijo.

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica

Comentarios: _____

**Participación de Vida para los Padres (LPP) ® (2005) Patricia E.
Fingerhut, OTR, PhD**

5. La necesidad de apoyo emocional de mi hijo me desgasta. (e.g. no poder entretenerse, fácilmente alterado, no puede tolerar el cambio en la rutina, etc.)

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica
-----------------------	------------	-------------------------	------------	-----------------------	--------------

Comentarios: _____

6. Soy capaz de satisfacer las necesidades emocionales de mi hijo.

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica
-----------------------	------------	-------------------------	------------	-----------------------	--------------

Comentarios: _____

7. Paso más tiempo del que quisiera, organizando los servicios para mi hijo. (por ejemplo, las citas con los profesionales de la salud, los servicios escolares, etc.).

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica
-----------------------	------------	-------------------------	------------	-----------------------	--------------

Comentarios: _____

8. Soy eficiente en conseguir servicios para mi hijo.

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica
-----------------------	------------	-------------------------	------------	-----------------------	--------------

Comentarios: _____

9. Paso más de mi tiempo del que yo gustaría organizando y ofreciendo actividades sociales para mi hijo. (por ejemplo, cosas que hacer, la gente con quien jugar etc.)

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica
-----------------------	------------	-------------------------	------------	-----------------------	--------------

Comentarios: _____

10. Yo soy eficiente en proveer actividades sociales para mi hijo.

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica
-----------------------	------------	-------------------------	------------	-----------------------	--------------

Comentarios: _____

**Participación de Vida para los Padres (LPP) ® (2005) Patricia E.
Fingerhut, OTR, PhD**

11. Soy capaz de manejar las tareas del hogar, mientras que cuido de mi hijo, (por ejemplo, el pago de facturas, la limpieza, hacer las comidas, lavar la ropa, etc).

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica
--------------------------	------------	----------------------------	------------	--------------------------	--------------

Comentarios: _____

12. Yo soy eficiente de hacer mandados con mi hijo. (e.g, ir de compras, al banco, las entregas).

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica
--------------------------	------------	----------------------------	------------	--------------------------	--------------

Comentarios: _____

13. Tener un hijo con necesidades especiales ha interferido con mi capacidad de mantener un trabajo o perseguir una educación.

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica
--------------------------	------------	----------------------------	------------	--------------------------	--------------

Comentarios: _____

14. Cuestiones financieras relacionadas con necesidades especiales de mi hijo son una fuente de estrés para nuestra familia.

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica
--------------------------	------------	----------------------------	------------	--------------------------	--------------

Comentarios: _____

15. Tener un hijo con necesidades especiales ha restringido mi habilidad para pasar tiempo con mi familia y amigos tan a menudo como me gustaría.

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica
--------------------------	------------	----------------------------	------------	--------------------------	--------------

Comentarios: _____

16. Pasar tiempo con mis amigos y familia con mi hijo presente es estresante.

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica
--------------------------	------------	----------------------------	------------	--------------------------	--------------

Comentarios: _____

**Participación de Vida para los Padres (LPP) ® (2005) Patricia E.
Fingerhut, OTR, PhD**

17. Tener un hijo con necesidades especiales restringe el tiempo que me gustaría pasar con mi cónyuge / pareja.

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica
-----------------------	------------	-------------------------	------------	-----------------------	--------------

Comentarios: _____

18. Tener un hijo con necesidades especiales restringe el tiempo que me gustaría pasar con mis otros hijos.

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica
-----------------------	------------	-------------------------	------------	-----------------------	--------------

Comentarios: _____

19. Tener un hijo con necesidades especiales afecta mi capacidad para participar en las actividades de la comunidad tan a menudo como me gustaría. (servicios religiosos, organizaciones de beneficencia, las organizaciones políticas o de la comunidad)

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica
-----------------------	------------	-------------------------	------------	-----------------------	--------------

Comentarios: _____

20. Tener un hijo con necesidades especiales ha afectado a mi salud.

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica
-----------------------	------------	-------------------------	------------	-----------------------	--------------

Comentarios: _____

21. Tener un hijo con necesidades especiales ha afectado mi descanso/dormir.

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica
-----------------------	------------	-------------------------	------------	-----------------------	--------------

Comentarios: _____

22. Tener un hijo con necesidades especiales afecta a mis oportunidades de participar en actividades personales. (aficiones, deportes y actividades recreativas)

Totalmente de Acuerdo	de acuerdo	de acuerdo y desacuerdo	desacuerdo	Totalmente desacuerdo	No se aplica
-----------------------	------------	-------------------------	------------	-----------------------	--------------

Comentarios: _____

**Participación de Vida para los Padres (LPP) ® (2005) Patricia E.
Fingerhut, OTR, PhD**

23. ¿Pensar en un día típico, existen otras actividades en las que te gustaría participar? ¿Cómo son estas actividades afectadas por tener un hijo con necesidades especiales?

Comentarios _____

APPENDIX C

Child Behavior Checklist 1.5-5

Achenbach & Rescorla, 2000



Please print.

CHILD BEHAVIOR CHECKLIST FOR AGES 1½-5

For official use only
or a

CHILD'S FULL NAME First Middle Last

CHILD'S GENDER

☐ Boy ☐ Girl

CHILD'S AGE

CHILD'S ETHNIC GROUP OR RACE

TODAY'S DATE

Mo. Day Year

CHILD'S BIRTHDATE

Mo. Day Year

PARENTS' USUAL TYPE OF WORK, even if not working now. Please be specific — for example, auto mechanic, high school teacher, homemaker, farmer, radio operator, shoe salesman, army sergeant.

PARENT 1 (or MOTHER)

TYPE OF WORK

PARENT 2 (or FATHER)

TYPE OF WORK

THIS FORM FILLED OUT BY: (print your full name)

Your relation to child:

☐ Parent 1 (or Mother)☐ Parent 2 (or Father)☐ Other (specify)

Please fill out this form to reflect your view of the child's behavior even if other people might not agree. Feel free to write additional comments beside each item and in the space provided on page 2. Be sure to answer all items.

Below is a list of items that describe children. For each item that describes the child now or within the past 2 months, please circle the 2 if the item is very true or often true of the child. Circle the 1 if the item is somewhat or sometimes true of the child. If the item is not true of the child, circle the 0. Please answer all items as well as you can, even if some do not seem to apply to the child.

0 = Not True (as far as you know)	1 = Somewhat or Sometimes True	2 = Very True or Often True
0 1 2	1. Aches or pains (without medical cause; do not include stomach or headaches)	0 1 2
0 1 2	2. Acts too young for age	0 1 2
0 1 2	3. Afraid to try new things	0 1 2
0 1 2	4. Avoids looking others in the eye	0 1 2
0 1 2	5. Can't concentrate, can't pay attention for long	0 1 2
0 1 2	6. Can't sit still, restless, or hyperactive	0 1 2
0 1 2	7. Can't stand having things out of place	0 1 2
0 1 2	8. Can't stand waiting; wants everything now	0 1 2
0 1 2	9. Chews on things that aren't edible	0 1 2
0 1 2	10. Clings to adults or too dependent	0 1 2
0 1 2	11. Constantly seeks help	0 1 2
0 1 2	12. Constipated; doesn't move bowels (when not sick)	0 1 2
0 1 2	13. Cries a lot	0 1 2
0 1 2	14. Cruel to animals	0 1 2
0 1 2	15. Defiant	0 1 2
0 1 2	16. Demands must be met immediately	0 1 2
0 1 2	17. Destroys his/her own things	0 1 2
0 1 2	18. Destroys things belonging to his/her family or other children	0 1 2
0 1 2	19. Diarrhea or loose bowels (when not sick)	0 1 2
0 1 2	20. Disobedient	0 1 2
0 1 2	21. Disturbed by any change in routine	0 1 2
0 1 2	22. Doesn't want to sleep alone	0 1 2
0 1 2	23. Doesn't answer when people talk to him/her	0 1 2
0 1 2	24. Doesn't eat well (describe):	0 1 2
0 1 2	25. Doesn't get along with other children	0 1 2
0 1 2	26. Doesn't know how to have fun; acts like a little adult	0 1 2
0 1 2	27. Doesn't seem to feel guilty after misbehaving	0 1 2
0 1 2	28. Doesn't want to go out of home	0 1 2
0 1 2	29. Easily frustrated	0 1 2
0 1 2	30. Easily jealous	0 1 2
0 1 2	31. Eats or drinks things that are not food — don't include sweets (describe):	0 1 2
0 1 2	32. Fears certain animals, situations, or places (describe):	0 1 2
0 1 2	33. Feelings are easily hurt	0 1 2
0 1 2	34. Gets hurt a lot; accident-prone	0 1 2
0 1 2	35. Gets in many fights	0 1 2
0 1 2	36. Gets into everything	0 1 2
0 1 2	37. Gets too upset when separated from parents	0 1 2
0 1 2	38. Has trouble getting to sleep	0 1 2
0 1 2	39. Headaches (without medical cause)	0 1 2
0 1 2	40. Hits others	0 1 2
0 1 2	41. Holds his/her breath	0 1 2
0 1 2	42. Hurts animals or people without meaning to	0 1 2
0 1 2	43. Looks unhappy without good reason	0 1 2
0 1 2	44. Angry moods	0 1 2
0 1 2	45. Nausea, feels sick (without medical cause)	0 1 2
0 1 2	46. Nervous movements or twitching (describe):	0 1 2
0 1 2	47. Nervous, fidgeting, or tense	0 1 2
0 1 2	48. Nightmares	0 1 2
0 1 2	49. Overeating	0 1 2
0 1 2	50. Overlaid	0 1 2
0 1 2	51. Shows panic for no good reason	0 1 2
0 1 2	52. Painful bowel movements (without medical cause)	0 1 2
0 1 2	53. Physically attacks people	0 1 2
0 1 2	54. Pokes nose, skin, or other parts of body (describe):	0 1 2

Be sure you answered all items. Then see other side.

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7-10-14 Edition 481

Please print your answers. Be sure to answer all items.

0 = Not True (as far as you know)	1 = Somewhat or Sometimes True	2 = Very True or Often True
0 1 2 55. Plays with own sex parts too much		0 1 2 79. Flap(s) shifts between sadness and excitement
0 1 2 56. Poorly coordinated or clumsy		0 1 2 80. Strange behavior (describe): _____
0 1 2 57. Problems with eyes (without medical cause) (describe): _____		0 1 2 81. Stubborn, sulky, or irritable
0 1 2 58. Punishment doesn't change his/her behavior		0 1 2 82. Sudden changes in mood or feelings
0 1 2 59. Quickly shifts from one activity to another		0 1 2 83. Sucks a lot
0 1 2 60. Rashes or other skin problems (without medical cause)		0 1 2 84. Talks or cries out in sleep
0 1 2 61. Refuses to eat		0 1 2 85. Temper tantrums or hot temper
0 1 2 62. Refuses to play active games		0 1 2 86. Too concerned with neatness or cleanliness
0 1 2 63. Repeatedly rocks head or body		0 1 2 87. Too fearful or anxious
0 1 2 64. Resists going to bed at night		0 1 2 88. Uncooperative
0 1 2 65. Resists toilet training (describe): _____		0 1 2 89. Underactive, slow moving, or lacks energy
0 1 2 66. Screens a lot		0 1 2 90. Unhappy, sad, or depressed
0 1 2 67. Seems unresponsive to affection		0 1 2 91. Unusually loud
0 1 2 68. Self-conscious or easily embarrassed		0 1 2 92. Upset by new people or situations (describe): _____
0 1 2 69. Selfish or won't share		0 1 2 93. Vomiting, throwing up (without medical cause)
0 1 2 70. Shows little affection toward people		0 1 2 94. Wakes up often at night
0 1 2 71. Shows little interest in things around him/her		0 1 2 95. Wanders away
0 1 2 72. Shows too little fear of getting hurt		0 1 2 96. Wants a lot of attention
0 1 2 73. Too shy or timid		0 1 2 97. Whining
0 1 2 74. Sleeps less than most kids during day and/or night (describe): _____		0 1 2 98. Withdrawn, doesn't get involved with others
0 1 2 75. Sneezes or plays with bowel movements		0 1 2 99. Waxes
0 1 2 76. Speech problem (describe): _____		0 1 2 100. Please write in any problems the child has that were not listed above.
0 1 2 77. Stares into space or seems preoccupied		0 1 2 _____
0 1 2 78. Stomachaches or cramps (without medical cause)		0 1 2 _____

*Please be sure you have answered all items.
Underline any you are concerned about.*

Does the child have any illness or disability (either physical or mental)? ☐ No ☐ Yes—Please describe:

What concerns you most about the child?

Please describe the best things about the child:

PAGE 2

APPENDIX D

Child Behavior Checklist 1.5-5 Spanish Version

(Achenbach & Rescorla, 2000)

Por favor utilice
letra de molde.

CUESTIONARIO SOBRE EL COMPORTAMIENTO DE NIÑOS(AS) DE 1½-5 AÑOS

Por favor conteste en la página
sigo

NOMBRE COMPLETO (Primer Nombre - Segundo Nombre - Apellido
DEL NIÑO(A))

SEXO

☐ Masculino ☐ Femenino

EDAD

GRUPO
ÉTNICO
O RAZA

FECHA DE HOY

Mes ____ Día ____ Año ____

FECHA DE NACIMIENTO

Mes ____ Día ____ Año ____

Por favor complete este cuestionario con su opinión sobre el
comportamiento de su hijo(a). Hágalo aunque usted piense que otras
personas no están de acuerdo con su opinión. Siéntase en la libertad de
escribir comentarios adicionales al final de cada frase y en el espacio que
se le brinda. **Asegúrese que contestó todas las preguntas.**

A continuación hay una lista de frases que describen a los(as) niños(as). Para cada frase que describe a su hijo(a) ahora o durante
los últimos dos meses, haga un círculo en el número 1 si la frase describe a su hijo(a) *mucho a menudo*. Haga un círculo en el número
2 si la frase describe a su hijo(a) *en cierta manera o algunas veces*. Haga un círculo en el 0 si la descripción con respecto a su hijo(a)
no es cierta. Por favor conteste todas las frases de la mejor manera posible. Incluya si algunas de ellas parecen no describir a su
hijo(a). **Por favor escriba en letra de molde. Asegúrese que contestó todas las preguntas.**

0 = No es cierto (que sepa usted)

1 = En cierta manera, algunas veces

2 = Muy cierto o cierto a menudo

- 0 1 2 1. Duele o molestia (sin causa médica; no
incluye dolor de estómago o dolor de cabeza)
- 0 1 2 2. Actúa como si fuera mucho menor que su edad
- 0 1 2 3. Tiene miedo de intentar cosas nuevas
- 0 1 2 4. Evita el contacto visual con otras personas
- 0 1 2 5. No puede concentrarse o prestar atención por
mucho tiempo
- 0 1 2 6. No puede quedarse quieta(s), es inquieto(a) o
hiperactivo(a)
- 0 1 2 7. No tolera que las cosas estén fuera de lugar
- 0 1 2 8. No puede esperar, lo quiere todo de inmediato
- 0 1 2 9. Masticó lo que no es comestible
- 0 1 2 10. Es demasiado dependiente o pegado(a) a los
adultos
- 0 1 2 11. Busca ayuda constantemente
- 0 1 2 12. Estreñido(a), no defeca (cuando no está
enfermo(a))
- 0 1 2 13. Lloró mucho
- 0 1 2 14. Es cruel con los animales
- 0 1 2 15. Desafiante
- 0 1 2 16. Sus necesidades deben ser satisfechas
inmediatamente
- 0 1 2 17. Destruye sus propias cosas
- 0 1 2 18. Destruye las cosas de sus familiares o de otras
personas
- 0 1 2 19. Tiene diarreas o heces líquidas (cuando no está
enfermo(a))
- 0 1 2 20. Desobediente
- 0 1 2 21. Cualquier cantidad de ruidos le perturba
- 0 1 2 22. No quiere dormir solo(a)
- 0 1 2 23. No contesta cuando la gente le habla
- 0 1 2 24. No come bien (describa) _____
- 0 1 2 25. No se lleva bien con otros niños(as)

- 0 1 2 26. No sabe divertirse, actúa como un pequeño
adulto
- 0 1 2 27. No parece sentirse culpable después de
portarse mal
- 0 1 2 28. No desea salir de casa
- 0 1 2 29. Se frustra fácilmente
- 0 1 2 30. Se pone caluroso fácilmente
- 0 1 2 31. Come o bebe cosas que no son alimento — no
incluye dulces (describa) _____
- 0 1 2 32. Tiene miedo de ciertas situaciones, animales o
lugares (describa) _____
- 0 1 2 33. Se asusta fácilmente
- 0 1 2 34. Se lastima accidentalmente con mucha
frecuencia, propenso a accidentes
- 0 1 2 35. Se mole mucho en peleas
- 0 1 2 36. Se mete en todo
- 0 1 2 37. Se molesta demasiado cuando lo separan de
sus padres
- 0 1 2 38. Tiene dificultad para quedarse dormido(a)
- 0 1 2 39. Dolores de cabeza (sin causa médica)
- 0 1 2 40. Lee pega a otras personas
- 0 1 2 41. Aguanta la respiración
- 0 1 2 42. Lee hace daño a otras personas o a animales
sin intención
- 0 1 2 43. Se ve triste sin razón aparente
- 0 1 2 44. Empedado(a)
- 0 1 2 45. Náuseas, se siente mal
- 0 1 2 46. Movimientos involuntarios o tics (describa) _____
- 0 1 2 47. Nervioso(a) o tenso(a)

Asegúrese que contestó todas las preguntas. Entonces vea al otro lado de esta página.

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5/02 version

Edición 7-23-00 600

Por favor utilice letra de molde. Asegúrese que contestó todas las preguntas.

0 = No es cierto (que sepa usted) 1 = En cierta manera, algunas veces 2 = Muy cierto o cierto a menudo

0	1	2	48.	Pasadillas	0	1	2	75.	Se urta o juega con excremento
0	1	2	49.	Coma demasiado	0	1	2	76.	Problemas para hablar o para pronunciar palabras (describa): _____
0	1	2	50.	Se comen demasiado	0	1	2	77.	Se queda mirando al vacío
0	1	2	51.	Muestra pánico sin ninguna buena razón	0	1	2	78.	Colores de estómago o retortijones (sin causa médica)
0	1	2	52.	Dolor al hacer sus necesidades (sin causa médica)	0	1	2	79.	Subitos cambios de tristeza a excitación
0	1	2	53.	Alata a la gente físicamente	0	1	2	80.	Comportamiento raro (describa): _____
0	1	2	54.	Se muerde el dedo en la nariz; se araña la piel u otras partes del cuerpo (describa): _____	0	1	2	81.	Oleadas de náuseas, malhumoradas, irritables
0	1	2	55.	Juega demasiado con sus partes sexuales	0	1	2	82.	Subitos cambios de humor o sentimientos
0	1	2	56.	Mala coordinación o torpeza	0	1	2	83.	Se pone de mal humor a menudo
0	1	2	57.	Problemas con los ojos (sin causa médica) (describa): _____	0	1	2	84.	Habla o flore mientras duerme
0	1	2	58.	El castigo no cambia su comportamiento	0	1	2	85.	Le dan náuseas o tiene mal gusto
0	1	2	59.	Pasa rápidamente de una actividad a otra	0	1	2	86.	Demasiado preocupado(a) por la limpieza o el orden
0	1	2	60.	Sarpullidos o irritación en la piel (sin causa médica)	0	1	2	87.	Demasiado ansioso(a) o miedoso(a)
0	1	2	61.	Se niega a comer	0	1	2	88.	Poco cooperador(a)
0	1	2	62.	Se niega a participar en juegos activos	0	1	2	89.	Poco activo(a), lento(a), o le falta energía
0	1	2	63.	Mueve repetidamente la cabeza o el cuerpo	0	1	2	90.	Inteligente o depridido(a)
0	1	2	64.	Se resista a ir a dormir en la noche	0	1	2	91.	Más ruidoso(a) de lo común
0	1	2	65.	Se resista a aprender a usar el inodoro (describa): _____	0	1	2	92.	Se molesta con situaciones nuevas o con gente nueva (describa): _____
0	1	2	66.	Grita mucho	0	1	2	93.	Vómitos (sin causa médica)
0	1	2	67.	Parece no reaccionar al estrés	0	1	2	94.	Se despierta con frecuencia durante la noche
0	1	2	68.	Se cohibe y se avergüenza con facilidad	0	1	2	95.	Vaga sin dirección
0	1	2	69.	Egoísta o se niega a compartir	0	1	2	96.	Quiere mucha atención
0	1	2	70.	Demuestra poco afecto hacia la gente	0	1	2	97.	Se queja mucho
0	1	2	71.	Demuestra poco interés por lo que la/o rodea	0	1	2	98.	Se aísla, no se relaciona con los demás
0	1	2	72.	Demuestra poco temor de hacerse daño	0	1	2	99.	Se preocupa mucho
0	1	2	73.	Demasiado tímido(a)	100.	Por favor anote cualquier otro problema que su niño(a) tenga y que no esté incluido en esta lista.			
0	1	2	74.	Duerme menos que la mayoría de los/as niños(as) durante el día y/o la noche (explique): _____	0	1	2	_____	
0	1	2	_____		0	1	2	_____	
0	1	2	_____		0	1	2	_____	

Por favor, asegúrese que contestó todas las preguntas **Subraye las que le preocupan**

¿Sufrir su hijo(a) de alguna enfermedad, o incapacidad física o mental? ☐ No ☐ Sí—por favor describa: _____

¿Qué es lo que más le preocupa con respecto a su hijo(a)? _____

¿Qué es lo mejor que ve en su hijo(a)? Por favor describa: _____

Página 2

APPENDIX E

Infant Toddler Sensory Profile™

Caregiver Questionnaire

English Version

Dunn & Daniels, 2002



INFANT/TODDLER SENSORY PROFILE™

Wendy Dunn, Ph.D., OTR, FAOTA
with Debra B. Daniels, MA, CCC-SLP

Caregiver Questionnaire 7 TO 36 MONTHS

Child's Name: _____

C: _____

E: _____

C: _____

14 24 34 44 54 64 74 84 94 104

Have there been more than 3 children, between the ages of birth-18 years, living in your household during the past 12 months? _____

INSTRUCTIONS

Please check the box that **best** describes the frequency with which your child does the following behaviors. Please answer all of the statements. If you are unable to comment because you have not observed the behavior or believe that it does not apply to your child, please draw an X through the number for that item. Write any comments at the end of each section.

Use the following key to mark your responses:

ALMOST ALWAYS	When presented with the opportunity, your child almost always responds in this manner, 90% or more of the time.
FREQUENTLY	When presented with the opportunity, your child frequently responds in this manner, about 70% of the time.
OCCASIONALLY	When presented with the opportunity, your child occasionally responds in this manner, about 50% of the time.
SELDOM	When presented with the opportunity, your child seldom responds in this manner, about 20% of the time.
ALMOST NEVER	When presented with the opportunity, your child almost never responds in this manner, 10% or less of the time.

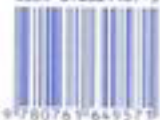
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Item	A. General Processing	Auditory Memory	Intelligence	Academic Achievement	Reading	Auditory Memory
1	My child's behavior deteriorates when the schedule changes.					
2	My child avoids playing with others.					
3	My child withdraws from situations.					

Note: You do not calculate a Raw Score Total for this section.

Comments:

Item	B. Auditory Processing	Auditory Memory	Intelligence	Academic Achievement	Reading	Auditory Memory
4	I have to speak loudly to get my child's attention.					
5	I have to touch my child to gain attention.					
6	My child enjoys making sounds with his/her mouth.					
7	My child takes a long time to respond, even to familiar voices.					
8	My child startsles easily at sound, compared to other children the same age.					
9	My child is distracted and/or has difficulty eating in noisy environments.					
10	My child ignores me when I am talking.					
11	My child tries to escape from noisy environments.					
12	My child finds ways to make noise with toys.					
13	It takes a long time for my child to respond to his/her name when it is called.					
Section Raw Score Total						

Comments:

Item	C. Visual Processing	Auditory Memory	Intelligence	Academic Achievement	Reading	Auditory Memory
14	My child enjoys looking at moving or spinning objects (for example, ceiling fans, toys with wheels, floor fans).					
15	My child enjoys looking at shiny objects.					
16	My child avoids eye contact with me.					
17	My child refuses to look at books with me.					
18	My child does not recognize self in the mirror.					
19	My child enjoys looking at own reflection in the mirror.					
20	My child prefers fast-paced, brightly colored TV shows.					
Section Raw Score Total						








Comments:

Item	D. Tactile Processing	Always/usually	Frequently	Occasionally	Rarely	Almost never
21	My child reacts being held.					
22	My child becomes agitated when having hair washed.					
23	My child avoids getting face/face exposed.					
24	My child is distressed when having hair trimmed.					
25	My child enjoys being cuddled.					
26	My child is overly charged in the bath water temperature, from one bath to the next.					
27	My child avoids contact with rough or cold surfaces (for example, against, against, cold).					
28	My child becomes very upset if own clothing, hands, and/or face are messy.					
29	My child gets upset with extreme differences in room temperature (for example, hot/cold).					
30	My child becomes anxious when walking or crawling on certain surfaces (for example, grass, sand, carpet, etc.).					
31	My child enjoys playing with food.					
32	My child seeks opportunities to feel vibrations (for example, stomps, splashes, washes, dries).					
33	My child bumps into things, seeming to not notice objects in the way.					
34	My child enjoys splashing during bath time.					
35	My child uses hands to explore food and other textures.					
Section Raw Score Total:						

Comments:

Item	E. Vestibular Processing	Always/usually	Frequently	Occasionally	Rarely	Almost never
36	My child requires more support for sitting than other children the same age (for example, infant seat, pillows, towel roll).					
37	My child enjoys physical activity (for example, bouncing, being held up high in the air).					
38	My child enjoys rhythmic activities (for example, swinging, rocking, car rides).					
39	My child becomes upset when placed on back to change diapers.					
40	My child resists having head tipped back during bathing.					
41	My child cries or frowns whenever I try to move hair/face.					
Section Raw Score Total:						

Comments:





Item	F. Oral Sensory Processing	Assess always				
		Never	Infrequently	Occasionally	Frequently	Almost always
 42	My child likes/chews on hard/soft objects.					
 43	My child mouths objects.					
 44	My child is unaware of food or liquid left on lips.					
 45	My child refuses all but a few food choices.					
 46	My child resists having teeth brushed.					
 47	My child refuses to drink from a cup.					
 48	My child refuses to try new foods.					
Section Raw Score Total						

Comments

What do you see as your child's strengths? _____

What are your concerns? _____

STOP HERE IF YOUR CHILD IS 7 TO 36 MONTHS OLD.

ICON KEY	
	Low Registration
	Sensation Seeking
	Sensory Sensitivity
	Sensation Avoiding

SCORE KEY	
1	Almost Always
2	Frequently
3	Occasionally
4	Seldom
5	Almost Never

APPENDIX F

Infant Toddler Sensory Profile™

Caregiver Questionnaire

Spanish version

Dunn & Daniels, 2002



INFANT/TODDLER SENSORY PROFILE™

Wendy Dunn, Ph.D., OTR, FAOTA
con Deborah B. Daniels, M.A., CCC-SLP

Cuestionario para padres o tutores

7 A 36 MESES

Nombre del niño/a: _____ Fecha de nacimiento: _____ Fecha: _____

Cuestionario llenado por: _____ Relación con el niño/a: _____

Nombre del proveedor de servicios: _____ Disciplina: _____

Ordene el orden en que nació su niño en la familia: primero segundo tercero cuarto quinto otro _____

¿Cuántos niños, recién nacidos hasta los 18 años, han vivido en su casa en los últimos 12 meses? _____

INSTRUCCIONES

Por favor, marque el cuadro que mejor represente la frecuencia con la cual su hijo/a demuestra los siguientes comportamientos. Si no le es posible comentar, porque no ha observado el comportamiento o porque piensa que no se aplica a su hijo/a, marque con una X el número correspondiente a esa situación. Escriba cualquier comentario al final de cada sección.

Use la siguiente clave para marcar sus respuestas:

CASI SIEMPRE

Cuando se le presenta la oportunidad, su hijo/a casi siempre responde de esta manera un 90% o más del tiempo.

FRECUENTEMENTE

Cuando se le presenta la oportunidad, su hijo/a frecuentemente responde de esta manera un 70% del tiempo.

A VECES

Cuando se le presenta la oportunidad, su hijo/a a veces responde de esta manera un 50% del tiempo.

RARAMENTE

Cuando se le presenta la oportunidad, su hijo/a raramente responde de esta manera un 20% del tiempo.

CASI NUNCA

Cuando se le presenta la oportunidad, su hijo/a casi nunca responde de esta manera un 10% o menos del tiempo.

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ISBN 076144961-5



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Item	A. Procesamiento General	Casi siempre	Frecuentemente	A veces	Raramente	Casi nunca
1	El comportamiento de mi hijo/ha se deteriora cuando hay cambios en su horario.					
2	Mi hijo/ha evita jugar con otros.					
3	Mi hijo/ha se retira de situaciones.					

Nota: Usted no califica los puntos de la escala de esta forma.

Comentarios

Item	B. Procesamiento Auditivo	Casi siempre	Frecuentemente	A veces	Raramente	Casi nunca
4	Tengo que hablar en voz alta para obtener la atención de mi hijo/ha.					
5	Tengo que tocar a mi hijo/ha para obtener su atención.					
6	A mi hijo/ha le gusta hacer sonidos con su boca.					
7	Mi hijo/ha toma mucho tiempo para responder, hasta con voces conocidas.					
8	Los sonidos suenan a mi hijo/ha fácilmente en comparación con niños de la misma edad.					
9	Mi hijo/ha se distrae y/o tiene dificultad para comer en ambientes ruidosos.					
10	Mi hijo/ha me ignora cuando le hablo.					
11	Mi hijo/ha trata de escapar de ambientes ruidosos.					
12	Mi hijo/ha encuentra formas de hacer sonidos con sus juguetes.					
13	Mi hijo/ha toma mucho tiempo para responder a su nombre cuando le hablan.					
Puntos de la sección						

Comentarios

Item	C. Procesamiento Visual	Casi siempre	Frecuentemente	A veces	Raramente	Casi nunca
14	A mi hijo/ha le gusta ver objetos que se mueven o giran (por ejemplo, abanicos de techo, juguetes con ruedas, ventiladores de pie).					
15	A mi hijo/ha le gusta ver objetos brillantes.					
16	Mi hijo/ha no me mira a los ojos.					
17	Mi hijo/ha evita ver libros conmigo.					
18	Mi hijo/ha no se reconoce en el espejo.					
19	Mi hijo/ha disfruta ver su imagen en el espejo.					
20	Mi hijo/ha prefiere programas de televisión con mucha acción y colores fuertes.					
Puntos de la sección						

Comentarios

Item		D. Procesamiento Tactil	Casi siempre	Frecuentemente	A veces	Raramente	Casi nunca
—	21	Mi hijo/ha se resiste a que lo/la sostengan.					
6	22	Mi hijo/ha se agita cuando le tocan el cabello.					
—	23	Mi hijo/ha evita que le impriman la carne/piel.					
6	24	Mi hijo/ha se angustia cuando le cortan las uñas.					
—	25	Mi hijo/ha se resiste a que lo/la abracen.					
6	26	Mi hijo/ha se resiste cuando hay cambios en la temperatura del agua del baño: de un baño poco al otro.					
—	27	Mi hijo/ha evita contacto con superficies ásperas o frías (por ejemplo: se resaca, se araña, hielo).					
6	28	Mi hijo/ha se enoja si está sucia su ropa, manos, o cara.					
6	29	Mi hijo/ha se disgusta con cambios extremos en la temperatura del ambiente (por ejemplo: mucho calor, mucho frío).					
6	30	Mi hijo/ha se pone ansioso/ansiosa cuando camina o gatea en ciertas superficies (por ejemplo: pasto/hierba, arena, alfombra).					
~	31	A mi hijo/ha le gusta jugar con la comida.					
~	32	Mi hijo/ha busca oportunidades para sentir vibraciones (por ejemplo: altura del estribo, lavadora, secadora).					
—	33	Mi hijo/ha choca con cosas, aparentemente sin notar objetos que están en su camino.					
~	34	A mi hijo/ha le gusta soplar agua cuando se baña.					
~	35	Mi hijo/ha usa sus manos para explorar la comida y otras texturas.					
Puntos de la sección							

Comentarios

Item		E. Procesamiento Vestibular	Casi siempre	Frecuentemente	A veces	Raramente	Casi nunca
—	36	Cuando se sienta, mi hijo/ha necesita más apoyo que otros niños de la misma edad (por ejemplo: silla para intentar, gimnasia).					
~	37	A mi hijo/ha le gustan las actividades físicas (por ejemplo: saltar, que lo/la levanten en el aire).					
~	38	A mi hijo/ha le gustan las actividades rítmicas (por ejemplo: columpiarse, bailar, viajes en automóvil).					
6	39	Mi hijo/ha se disgusta cuando lo/la presionen de espaldas para cambiar sus pañales.					
—	40	Mi hijo/ha resiste que le muevan la cabeza hacia atrás cuando lo/la bañan.					
6	41	Mi hijo/ha forcea o se resiste cuando lo/la trato de mover.					
Puntos de la sección							

Comentarios

Item		F. Procesamiento Sensorial Oral	Casi Siempre	Frecuentemente	A Veces	Raramente	Casi Nunca
	42	Mi hijo/ha tiene muchos objetos que no son comibles.					
	43	Mi hijo/ha juega con objetos en la boca.					
	44	Mi hijo/ha no nota la comida o líquido que se le queda en sus labios.					
	45	Mi hijo/ha rechaza casi toda la comida.					
	46	Mi hijo/ha se resiste o que le duelen los dientes.					
	47	Mi hijo/ha rechaza tomar de una taza.					
	48	Mi hijo/ha rechaza probar comidas nuevas.					
Puntaje de la sección							

Comentarios:

¿Qué es lo que usted ve como los puntos fuertes o virtudes de su niño/niña? _____

¿Cuáles son sus preocupaciones o puntos débiles de su niño/niña? _____

PARA AQUÍ SI SU NIÑO/NIÑA TIENE 7 A 24 MESES DE EDAD.

ICON KEY	
	Regreso Bajo
	Detección de Sentidos
	Sensibilidad Sensoria
	Estado Sensorial

SCORE KEY	
1	Casi Siempre
2	Frecuentemente
3	A Veces
4	Raramente
5	Casi Nunca

APPENDIX G

Parent Consent to Participate in Study-English Version

Code _____



04-Dec-2014-
21-Nov-2015



Patricia E. Fingerhut, OTR, PhD, Associate Professor and Chair
Department of Occupational Therapy
3.920 School of Health Professions Bldg.
301 University Boulevard, Galveston, Texas, 77555-1142

Elaina DaLomba, PhD-C
Easter Seals of San Antonio
2203 Babcock Rd.
San Antonio, TX 78229

CONSENT TO PARTICIPATE

You are being asked to participate as a subject in the research project entitled, *The Life Participation for Parents as an Outcome Measure* under the direction of Patricia Fingerhut, OTR, PhD, Associate Professor and chair of the Occupational Therapy Program at the University of Texas Medical Branch.

PURPOSE OF THE STUDY

Raising a child with special needs can have an affect on a parent's time and daily activities. This study will look at how parents who are raising a child with special needs are able to get their daily activities done. The purpose of this study is to create a tool to make therapy more family-centered. You are being asked to take part in this study because you are the parent or caregiver of a child with special needs.

PROCEDURES RELATED ONLY TO THE RESEARCH

You are asked to complete questionnaires about how you get everyday activities done while you care for your child. If the questionnaire identifies an issue, you will create a goal with your occupational therapist to address that issue. You will be asked to complete the questionnaire again after 3 months. If your child will be finished with therapy sooner, you will fill out the second questionnaire in your last session. The *Life Participation for Parents (LPP)* questionnaire is attached to this letter. Everyone will complete this form. If your child is less than 3 years old, you will also be asked to fill out two other forms. These are the *Infant Toddler Sensory Profile (ITSP)* and the *Child Behavior Checklist (CBCL)*. These forms will look at the behavior of children to see how it affects parents getting their daily activities done. You should not write your names or any information that would let others know who you are on the questionnaires. All of the questionnaires should go back to your occupational therapist.

PROCEDURES NOT RELATED TO THIS RESEARCH (i.e., standard of care)

This study, and your participation in it, will not change your regular occupational therapy. You will continue to receive your current level and kind of occupational therapy. Being a part of this study will not mean you have to come to therapy any more or less often than you have been.

RISKS OF PARTICIPATION

The potential risks for participating in this study are very small. There is only the time required to fill out the questionnaire and unexpected loss of confidentiality.

NUMBER OF SUBJECTS PARTICIPATING AND THE DURATION OF YOUR PARTICIPATION

The anticipated number of subjects involved in the study will be 60 families from occupational therapy programs throughout Texas. Your occupational therapist will monitor the goal you set for 3 months to

Last Revised: 9/29/11

Page 1 of 4

Code _____
collect more data. This will not have any effect on the length of time your child is in therapy which will be determined by you and your therapist.

BENEFITS TO THE SUBJECT

When you complete the questionnaires, you may find new areas that you can work on in occupational therapy. You will get to see the changes your family makes in how well you are able to get daily activities done. However, you may also find there is no benefit to taking part in the study.

OTHER CHOICES (ALTERNATIVE TREATMENT)

The only alternative action for the study is for you not to participate.

SAFE WITHDRAWAL FROM THE STUDY

You may choose not to participate or to withdraw from this study at any time. Participating or not participating will not affect your child's therapy services in any way. You can change your mind and stop participating and this will not affect your occupational therapy treatment either.

REIMBURSEMENT FOR EXPENSES/COSTS OF PARTICIPATION

There is no cost to you for participating in this study. It will be completed as a part of your regular occupational therapy evaluation and treatment sessions. No reimbursement will be needed.

COMPENSATION FOR RESEARCH-RELATED INJURY

No injuries are expected through completing these questionnaires. University policy requires the following statement:

If you are physically injured because of any procedure properly performed on you under the plan for this study, your injury will be treated. Compensation for an injury resulting from your participation in this research is not available from the University of Texas Medical Branch at Galveston or Texas Woman's University. You, or your insurance company or health care plan, will be billed and you will be responsible for any charges. The researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will help you. However, UTMB and TWU do not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

USE AND DISCLOSURE OF YOUR HEALTH INFORMATION

No personally identifiable information will be used in this study. You should not enter your names or any other information that might let others know who you are on the questionnaires. Your questionnaire(s) will be coded with a number. Only your occupational therapist will see your answers. By signing this consent form, you are authorizing the use and disclosure of your responses related to the research study. Except when required by law, you will not be identified by name, social security number, address, telephone number, or any other direct personal identifier in study records disclosed outside of the University of Texas Medical Branch (UTMB). Only coded questionnaires will be used outside of your therapy clinic or home. You will be assigned a unique code number. The key to the code will be kept in a locked file in Dr. Fingerhut's office.

If you change your mind later and do not want us to collect or share your health information, you need to contact the researcher listed on this consent form by telephone. You need to say that you have changed your mind and do not want the researcher to collect and share your information. The results of this study may be published in scientific journals without identifying you by name.

ADDITIONAL INFORMATION

Last Revised: 9/19/11

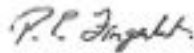
Code _____

1. If you have any questions, concerns or complaints before, during or after the research study, or if you need to report a research related injury or adverse reaction (bad side effect), you should immediately contact Dr. Fingerhut's office at 409-772-3061 or Elaine DeLomba at 210-573-6156.
2. Your participation in this study is completely voluntary and you have been told that you may refuse to participate or stop your participation in this project at any time without penalty or loss of benefits and without jeopardizing your occupational therapy. If you decide to stop your participation in this project and revoke your authorization for the use and disclosure of your information, UTMB may continue to use and disclose your information in some instances. This would include any information that was used or disclosed prior to your decision to stop participation and needed in order to maintain the integrity of the research study. If there are significant new findings or we get any information that might change your mind about participating, we will give you the information and allow you to reconsider whether or not to continue.
3. If you have any complaints, concerns, input or questions regarding your rights as a subject participating in this research study or you would like more information, you may contact the Institutional Review Board Office, at (409) 266-9475.

Informed consent is required of all persons in this project. Whether or not you provide a signed informed consent for this research study will have no effect on your current or future relationship with your occupational therapist, UTMB or TWU.

The purpose of this research study, procedures to be followed, risks and benefits have been explained to you. You have been allowed to ask questions and your questions have been answered to your satisfaction. You have been told who to contact if you have additional questions. You have read this consent form and voluntarily agree to participate as a subject in this study. You are free to withdraw your consent, including your authorization for the use and disclosure of your health information, at any time. You may withdraw your consent by notifying Dr. Fingerhut's office at 409-772-3061.

If you are willing to participate please sign the consent form and return to the researcher. You may keep this letter for your information. Thank you.



Patricia Fingerhut, OTR, PhD

Code _____

I agree to participate in the research project entitled *The Life Participation for Parents as an Outcome Measure*.

Signature of Subject

Date

Using language that is understandable and appropriate, I have discussed this project and the items listed above with the subject.

Date

Signature of Person Obtaining Consent

APPENDIX H

Parent Consent to Participate in Study-Spanish Version

Patricia E. Fingerhut, OTR, PhD, Associate Professor and Chair
Department of Occupational Therapy
3.920 School of Health Professions Bldg.
301 University Boulevard, Galveston, Texas, 77555-1142

Elaina DuLomba, PhD-C
Easter Seals of San Antonio
2203 Babcock Rd.
San Antonio, TX 78229

CONSENTIMIENTO PARA PARTICIPAR

Se le pide participar como sujeto en el proyecto de investigación titulado, La Participación de Vida para Padres (titulado en inglés como "The Life Participation for Parents o LPP") como una medida de resultado bajo la dirección de Patricia Fingerhut, OTR, PhD, Profesor Asociado y director del Programa de Terapia Ocupacional de la Universidad de Texas Medical Branch.

PROPÓSITO DEL ESTUDIO

La crianza de un(a) niño(a) con necesidades especiales puede tener un efecto en el tiempo de los padres y las actividades diarias. Este estudio investigará cómo los padres que están criando a un(a) niño(a) con necesidades especiales son capaces de obtener sus actividades diarias realizadas. El propósito de este estudio es crear una herramienta para hacer la terapia más centrada en la familia. Se le pide su participación en este estudio porque usted es el padre o cuidador de un(a) niño(a) con necesidades especiales.

PROCEDIMIENTOS RELACIONADOS SÓLO EN LA INVESTIGACIÓN

Se le pedirá completar cuestionarios acerca de cómo usted consigue realizar las actividades diarias mientras usted cuida de su hijo(a). Si el cuestionario identifica un problema, va a crear una meta con su terapeuta ocupacional para abordar ese asunto. Se le pedirá que complete el cuestionario de nuevo después de 3 meses. Si su niño(a) terminará con la terapia antes del tiempo determinado, usted llenará el segundo cuestionario en la última sesión. El cuestionario de la "Participación de Vida para los Padres" (LPP) se adjunta a la presente carta. Todo el mundo va a terminar este formulario. Si su hijo(a) tiene menos de 3 años de edad, también se le pedirá que llene otras dos formas. Estos son el Perfil infantil del niño Sensorial (ITSP) y la lista de comportamiento del Niño(a) (titulados en inglés como "the Infant/Toddler Sensory Profile" o ITSP) and the Child Behavior Checklist o CBCL") Estos formularios evalúan el comportamiento de los niños para ver cómo afecta a los padres en lograr realizar sus actividades diarias. Usted no deben escribir sus nombres o cualquier información que permitiría que los demás sepan que usted está en los cuestionarios. Todos los cuestionarios deben volver a su terapeuta ocupacional.

PROCEDIMIENTOS NO RELACIONADOS CON ESTA INVESTIGACIÓN (es decir, nivel de atención)

Este estudio, y su participación en el mismo, no va a cambiar su terapia ocupacional regular. Continuará recibiendo su nivel y tipo de terapia ocupacional actual. Ser parte de este estudio no significa que usted tiene que venir a la terapia más o menos frecuencia de lo que lo ha realizado.

RIESGOS DE PARTICIPACIÓN

Los riesgos potenciales para participar en este estudio son muy pequeños. Sólo es el tiempo requerido para llenar el cuestionario y la potencial pérdida inesperada de la confidencialidad.

NÚMERO DE SUJETOS PARTICIPANTES Y LA DURACIÓN DE SU PARTICIPACIÓN

El número previsto de los sujetos involucrados en el estudio será de 60 familias de programas de terapia ocupacional a través de Texas. Su terapeuta ocupacional supervisará la meta que estableció durante 3 meses para obtener más datos. Esto no tiene ningún efecto sobre la duración del tiempo que su hijo(a) está en terapia el cual será determinado por usted y su terapeuta.

BENEFICIOS PARA EL TEMA

Al completar los cuestionarios, puede encontrar nuevas áreas que se pueden trabajar durante las terapias. Usted verá los cambios que su familia hace y en lo bien que son capaces de obtener las actividades realizadas diariamente. Sin embargo, también se puede encontrar que no hay un beneficio por tomar parte en el estudio.

OTRAS OPCIONES (TRATAMIENTO ALTERNATIVO)

La única acción alternativa para el estudio es que no participe.

RETIRADA SEGURA DEL ESTUDIO

Usted puede optar por no participar o retirarse de este estudio en cualquier momento. Participar o no ser participante no afectará a los servicios de terapia de su hijo(a) de cualquier manera. Usted puede cambiar de opinión, dejar de participar y esto no afectará su tratamiento de terapia ocupacional tampoco.

REEMBOLSO DE LOS GASTOS/COSTOS DE LA PARTICIPACIÓN

No hay ningún costo para usted por participar en este estudio. Será realizado como parte de sus sesiones habituales de evaluación y tratamiento de terapia ocupacional. Ningún reembolso será necesario.

COMPENSACIÓN DE INVESTIGACIONES RELACIONADAS CON LESIONES

No hay lesiones que se espera a través del proceso de completar estos cuestionarios. La política de la Universidad requiere la siguiente declaración:

Si usted está físicamente lesionado(a) a causa de cualquier procedimiento correctamente realizado sobre usted bajo el plan para este estudio, se tratará su lesión. La compensación por los daños subsiguientes a su participación en esta investigación no está disponible en la Universidad de Texas Rama Médica Galveston (titulada en inglés como "University of Texas Medical Branch o UTMB") o en la Texas Universidad de la Mujer (titulada en inglés como "Texas Woman's University o TWU"). Se le facturará a usted o su plan de seguro de atención médica, y usted será responsable por cualquier cargo. Los investigadores tratarán de evitar cualquier problema que podría ocurrir debido a esta investigación. Usted debe dejar a los investigadores saber de inmediato si hay un problema y en que se puede ayudar. Sin embargo, UTMB y TWU no proporcionan servicios médicos o ayuda financiera para las lesiones que podría suceder porque usted este tomando parte en esta investigación.

USO Y DIVULGACIÓN DE SU INFORMACIÓN DE SALUD

No hay información de identificación personal que será utilizado en este estudio. No debe introducir sus nombres o cualquier otra información que los demás puedan separ que usted está en los cuestionarios. Su cuestionario(s) se codifica con un número. Sólo su terapeuta ocupacional verá sus respuestas. Al firmar este formulario de consentimiento, usted autoriza el uso y divulgación de las respuestas relacionadas con el estudio de investigación. Excepto cuando sea requerido por la ley, usted no será identificado por su nombre, número de seguro social, dirección, número de teléfono, o cualquier otro medio de identificación personal directo en los registros del estudio divulgado fuera del Centro Médico de la Universidad de Texas Rama Médica. Solamente los cuestionarios codificados serán utilizados fuera de su clínica de terapia o en el hogar. Se le asignará un número de código único. La clave para el código se mantiene en un archivo bloqueado en el consultorio del Dr. Fingerhut.

Si cambia de opinión más adelante y no desea que recopilemos ni compartamos su información de salud, usted necesita ponerse en contacto con el investigador que aparece en este formulario de consentimiento por teléfono. Es necesario decir que ha cambiado de opinión y no quiere que el investigador recolecte y comparta su información. Los resultados de este estudio pueden ser publicados en revistas científicas sin identificarlo por su nombre.

INFORMACIÓN ADICIONAL

1. Si usted tiene alguna pregunta, duda o queja antes, durante o después del estudio de investigación, o si necesita reportar una lesión relacionada con la investigación o reacción adversa (efecto secundario malo), se debe comunicar inmediatamente con la oficina del Dr. Fingerhut en 409-772-3061 o Ilaina DeLomba en 210-573-6156.

2. Su participación en este estudio es completamente voluntaria y se le ha dicho que usted puede negarse a participar o dejar de participar en este proyecto en cualquier momento sin penalidad o pérdida de beneficios y sin poner en peligro su terapia ocupacional. Si usted decide dejar su participación en este proyecto y revocar su autorización para el uso y divulgación de su información, UTMB puede continuar utilizando y divulgando su información en algunos casos. Esto incluye cualquier información que fue utilizada o divulgada antes de su decisión de dejar su participación en el estudio con el fin de mantener la integridad del estudio de investigación. Si hay nuevos hallazgos significativos o

que reciben cualquier información que pudiera cambiar de opinión acerca de participar, le daremos la información y permitir a reconsiderar si debe o no continuar.

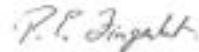
3. Si usted tiene alguna queja, inquietud, opinión o pregunta sobre sus derechos como sujeto participar en este estudio de investigación o desea más información, puede comunicarse con la Oficina de la Junta de Revisión Institucional, al (409) 266-9475.

El consentimiento informado es un requisito para todas las personas en este proyecto. Si usted proporciona un consentimiento informado firmado o no para este estudio de investigación, no tendrá ningún efecto sobre su relación actual o futura con su terapeuta ocupacional en las instituciones de UTMB o TWU.

El propósito de este estudio de investigación, los procedimientos a seguir, los riesgos y los beneficios han explicado usted. Se le ha permitido para hacer preguntas y las mismas han sido contestadas a su satisfacción. Se les ha dicho a quién contactar si tiene preguntas adicionales. Usted ha leído este formulario de consentimiento y voluntariamente está de acuerdo en participar como un sujeto en este estudio. Usted es libre de retirar su consentimiento, incluyendo su autorización para el uso y divulgación de su información de salud, en cualquier momento. Usted puede retirar su consentimiento mediante notificación a la oficina de Dr. Fingerhut al 409-772-3061.

Si usted está dispuesto a participar, por favor firmar el formulario de consentimiento y regresar al investigador. Puede mantener esta carta para su información. Gracias.

Patricia Fingerhut, OTR, PhD



Code _____

Yo estoy de acuerdo en participar en el proyecto de investigación titulado "La Participación Vida para Padres como una medida de resultado".

Firma del sujeto

Fecha

Se ha usado un lenguaje comprensible y adecuado, yo he hablado de este proyecto y los elementos enumerados anteriormente con el tema.

Fecha

Firma de la persona que obtiene el consentimiento

APPENDIX I

Therapist Consent To Participate

Patricia E. Fingerhut, OTR, PhD, Associate Professor and Chair
Department of Occupational Therapy
3.920 School of Health Professions Bldg.
301 University Boulevard, Galveston, Texas, 77555-1142

Elaina DeLomba, OTR, PhD-C
Easter Seals of San Antonio
2203 Balcock Rd.
San Antonio, TX 78229

RESEARCH CONSENT FORM

You are being asked to participate as a subject in the research project entitled, *The Life Participation for Parents (LPP) as an Outcome Measure* under the direction of Patricia Fingerhut, OTR, PhD, Associate Professor and Chair of the Occupational Therapy Department at the University of Texas Medical Branch.

PURPOSE OF THE STUDY

The purpose of this study is to develop a tool to make therapy more family-centered. Raising a child with special needs can affect a parent's time and daily activities. This questionnaire is to find out what issues parents are having. You have been recruited because you are an occupational therapist working with parents or caregivers of children with special needs.

PROCEDURES RELATED TO THE RESEARCH

Thirty OTs and sixty parents will be recruited to participate in this study, which should be completed within one year. You are being asked to choose two parents from your current clients that may be having difficulty participating in life occupations of caring for their child, balancing activities, participating in social events etc. related to their child's special needs. See the LPP questionnaire for specific issues. Ask these parents to complete the LPP and consent to participate form and return to you. If these parents have identified an issue that you believe would be amenable to a family-centered goal and intervention please enroll them in the study and proceed with the study protocol. If no issue is evident please discuss the results with the parent, explain why they are not appropriate for the study, and recruit another parent to participate so that you enroll two parents in the study. The study researchers will be available by phone, e-mail or visits to your site to assist you in designing family-centered goals and intervention or to answer any questions.

PROCEDURES NOT RELATED TO THIS RESEARCH (i.e., standard of care)

If the family does not qualify for or choose to participate in the study you should continue to offer planned and appropriate occupational therapy services for them. However, do not include them in study data.

RISKS OF PARTICIPATION

The risks to participating in this study are minimal. One of the risks you may face is a loss of time from administering and scoring the questionnaire, however the information gained from this is typical to that sought in most occupational therapy evaluations.

BENEFITS TO THE SUBJECT

You may discover new ways of inquiring about parent participation, and therefore planning interventions for them, from participating in this study. You may also receive no direct benefit from this study.

SAFE WITHDRAWAL FROM THE STUDY

Code _____

Participation in this study is voluntary. You may choose not to participate or to withdraw from it at any time with no consequence to you or the families you treat.

REIMBURSEMENT FOR EXPENSES/COSTS OF PARTICIPATION

All questionnaires will be delivered to you. There are no specific expenses or costs outside of these, therefore no reimbursement is offered for this study.

COMPENSATION FOR RESEARCH RELATED INJURY

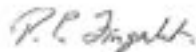
No injuries are anticipated through participation in this study. University regulations require the inclusion of the following statement.

If you are physically injured because of any procedure properly performed on you under the plan for this study, your injury will be treated. Compensation for an injury resulting from your participation in this research is not available from the University of Texas Medical Branch at Galveston or Texas Woman's University. You, or your insurance company or health care plan, will be billed and you will be responsible for any charges. The researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will help you. However, UTMB and TWU do not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

All information will be confidential. You will not be identified in the final write up or publication of the study results. All research information will be kept in a locked file cabinet or on a password protected computer by Dr. Fingerhut. The only anticipated risks are your time to complete the study protocol and unexpected breach of confidentiality.

You may choose not to participate or to withdraw from this study at any time. The study is conducted by Patricia Fingerhut, (Associate professor and OT Chair at UTMB) and Elaine Datamba, (doctoral candidate at TWU). If you have any questions please contact Dr. Patricia Fingerhut, principal investigator, 409-772-3061. If you have any questions about your rights as a participant in this research or the way this study has been conducted, please contact the University of Texas Medical Branch Office of Research, 409-266-9475.

If you are willing to participate please sign the consent form and return to the researcher. You may keep this letter for your information. Thank you.



Patricia Fingerhut, OTR, PhD

Code _____

The Life Participation for Parents (LPP) as an Outcome Measure

I have read and understand the information about this study. I understand family-centered intervention and am able to follow the study protocol as explained by the researchers. I agree to participate.

participant's name

participant's signature

date

APPENDIX J

Institutional Authorization Agreement

An Institutional Authorization Agreement (IAA) has been processed for the above referenced IRB protocol (see attached).



Institutional Review Board
Office of Research
5701 Fossil, Houston, TX 77056
713 (794-2480)
research@twu.edu
http://www.twu.edu/irb.html

DATE: January 27, 2015

TO: Ms. Diana Delumbia
Occupational Therapy - Houston

FROM: Ms. Tracy Lindsey, Director of Operations
Office of Research & Sponsored Programs

Re: Institutional Authorization Agreement (IAA) Processed for The Life Participation for Parents
(LPP) as an Outcome Measure (Protocol #: 16001)

An IAA for the above referenced study between Texas Woman's University and University of Texas Medical Branch (UTMB) has been processed as an expedited study. The University of Texas Medical Branch (UTMB) IRB is the designated IRB providing the review for this study. According to our records, this protocol was approved by the University of Texas Medical Branch (UTMB) IRB on 11/21/2014.

A current protocol file with all correspondence between the researcher and the University of Texas Medical Branch (UTMB) IRB must be maintained at TWU. Therefore, you are required to place on file any documentation regarding this study including modifications, extensions, notifications of adverse events, etc.

If you have any questions, please contact the TWU IRB.

cc: Dr. Patricia Bowyer, Occupational Therapy - Houston
Dr. Mary Francis (Francine) Baefar, Occupational Therapy - Houston
Graduate School
Dr. Patricia Fagerhut

APPENDIX K

Request For Expedited Research –University of Texas Medical Branch

Page 2

1. Expected Research Category

Designate the category that qualifies this proposal for expedited review, and justify this designation by responding to the statements below each category.

Category # 7

Information Required for Justification (See specific information below, required for each category):

1. Individual behavior

2. Survey / questionnaires

EXPEDITED RESEARCH CATEGORIES

The following types of research may be reviewed by the IRB (IRB) under an expedited review procedure (45 CFR 46.108 and 21 CFR 31.110). These research activities:

(1) Present no more than minimal risk to human subjects;

(2) Involve only procedures listed in one or more of the below categories;

(3) The identification of subjects or their responses will not reasonably place them at risk of criminal or civil liability or be damaging to their financial standing, employability, insurability, reputation or be stigmatizing, unless reasonable and appropriate protections will be implemented so that the risks related to invasion of privacy and breach of confidentiality are no greater than minimal; and

(4) The research is not classified.

CATEGORY 1

Oral studies of drugs and/or devices only when:

(a) Research on drugs for which an investigational new drug (IND) application is not required (21 CFR Part 312); (Note: Research on marketed drugs that significantly increases the risks or decreases the acceptability of the risks associated with the use of the product is not eligible for expedited review.) **OR**

(b) Research on medical devices for which:

(i) an investigational device exemption application (IDE) is not required (21 CFR Part 812); **OR**

(ii) the medical device is cleared/approved for marketing and the medical device is being used in accordance with its cleared/approved labeling.

Information Required for Justification:

1. State the name of the substantially available drug to be used as described in the above requirements; **OR**

2. State the name of the approved device and confirm its use as described above.

3. Confirm that the research does not increase the risks or decrease the acceptability of the risks associated with the use of the product.

CATEGORY 2

Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture as follows:

(a) From healthy, non-pregnant adults who weigh at least 110 pounds: For these subjects, the amount drawn may not exceed 100 ml in an 8 week period and collection may not occur more frequently than 2 times per week; **OR**

(b) From other adults and children* considering the age, weight, and health of the subjects, the collection procedure, the amount of blood to be collected, and the frequency with which it will be collected. For these subjects, the amount drawn may not exceed the lesser of 90 ml or 5 ml per kg in an 8 week period and collection may not occur more frequently than 2 times per week.

Information Required for Justification:

1. State how the most complex will be collected.

2. Provide the health status of the research population and state whether pregnant women are eligible to participate.

OR **For Adults, non-pregnant adults who weigh at least 110 pounds:**

Confirm that the amount of blood to be drawn will not exceed 100 ml in an 8 week period and will not occur more frequently than 2 times per week.

OR **For other adults (i.e., with an illness or children*:**

Confirm that the amount of blood to be collected will not exceed the lesser of 90 ml or 5 ml per kg in an 8 week period and will not occur more frequently than 2 times per week.

*Children are defined in the IRB regulations as "persons who have not attained the legal age for consent to treatments or procedures involved in the research, under the applicable law of jurisdiction in which the research will be conducted." 45 CFR 46.402(a).

CATEGORY 3

Prospective collection of biological specimens for research purposes by non-invasive means. Examples:

(a) hair and nail clippings in a non-donating manner;

(b) deciduous teeth at time of extraction or if routine patient care indicates a need for extraction;

(c) permanent teeth if routine patient care indicates a need for extraction;

(d) excreta and external secretions (including sweat);

(e) unstimulated saliva collected either in an unstimulated fashion or stimulated by chewing gum or by sucking a sterile cloth solution in the tongue;

(f) placenta removed at delivery;

(g) amniotic fluid obtained at the time of rupture of the membrane prior to or during labor;

(h) supra- and subgingival dental plaque and calculus, provided the collection procedure is not more invasive than routine prophylactic scaling of the teeth and the process is accomplished in accordance with accepted prophylactic techniques;

(i) mucosal and skin cells collected for buccal scraping or swab, skin swab, or mouth washings;

(j) sputum collected after active chest auscultation.

Information Required for Justification:

CATEGORY 1

The collection of data through noninvasive procedures (not involving general anesthesia or sedation) postmarket surveillance in clinical practice, including procedures involving a visit or encounter, where medical devices are employed, they must be cleared/approved for marketing. Studies intended to evaluate the safety and effectiveness of the medical device are not generally eligible for expedited review, including studies of cleared medical devices for new indications.)

Examples of such procedures:

- (1) physical contact applied to the surface of the body or at a distance and do not involve input of significant amounts of energy into the subject or an invasion of the subject's privacy;
- (2) weighing or testing sensory acuity;
- (3) magnetic resonance imaging (MRI);
- (4) electrocardiography (ECG or EKG);
- (5) thermography;
- (6) detection of naturally occurring radioactivity;
- (7) electroencephalography;
- (8) ultrasound;
- (9) diagnostic retinal imaging;
- (10) Doppler blood flow;
- (11) echocardiograms;
- (12) moderate exercise... where appropriate, given age, weight, and health of the individual.

Information Required for Justification

1. State the type of data to be collected.
2. State the source of the data and the procedure that will be used to collect the data.

CATEGORY 2

Research involving materials (data, documents, records, or specimens) that have been, or will be, collected solely for non-research purposes such as medical treatment or diagnosis. (Note: Some research in this category may be exempt from the FDSS regulations for the protection of human subjects, 40 CFR 40.101(b)(2). This listing refers only to research that is not exempt.)

Information Required for Justification

1. State the type of materials and the purpose for which it was, or will be, collected.
2. State the source of the material and whether it is currently existing (i.e., on the shelf at the present time) or will be collected prospectively.

CATEGORY 3

Collection of data from voice, video, digital, or image recordings made for research purposes.

Information Required for Justification

1. State the type of data and its original (primary or secondary) purpose(s); how data will be stored; and who will have access.
2. State whether there will be identifiable information on the tapes and when the tapes will be destroyed.

CATEGORY 4

Research on individual or group characteristics or behavior including, but not limited to, research on:

- | | | |
|--|----|--|
| <ul style="list-style-type: none"> (1) perception, (2) cognition, (3) motivation, (4) identity, (5) language, (6) communication, (7) cultural beliefs or practices, and (8) social behavior. | or | <p><u>Research activities include:</u></p> <ul style="list-style-type: none"> (1) survey (2) interview (3) oral history (4) focus group (5) program evaluation (6) human factors evaluation, or (7) quality assurance methodologies |
|--|----|--|

(Note: Some research in this category may be exempt from the FDSS regulations for the protection of human subjects, 40 CFR 40.101(b)(2) and (b)(3). This listing refers only to research that is not exempt.)

Information Required for Justification

1. State whether this is research on individual or group characteristics or behavior.
2. State the method to be used to gather the data.

NOTE: Your research is reviewed, scientifically, with an expedited review allowance if the research was originally submitted under an expedited review system. If expedited review was required to complete a Request for Determination, please notify the regulatory authorities for continuing review of research.

Page 4

5. Summary of Research

(a) Describe the research (background, objectives, and description of how research will be conducted) in research language. (10%) If this research is a retrospective chart review (Category 5 - medical records review in either a hard copy or electronic format, it is subject to the requirements of Health Insurance Portability and Accountability Act (HIPAA) and page 6 of this form must also be completed. In addition, include a copy of the data collection sheet. The data collection sheet should not include subject identifiers.

1. Introduction and Purpose:

The Life Participation for Parents (LPP; 2005) is an assessment tool designed to measure a parent's ability to participate in daily life while raising a child with special needs. Previous studies have indicated the effectiveness of the instrument in providing valuable information for designing family-centered goals and intervention (Fingerhut, 2009; Fingerhut, 2012). Further investigation is needed to determine if the instrument is sensitive enough to measure change after intervention. This study is designed to further discuss the LPP as an assessment for providing family-centered intervention for children with special needs and their families and to investigate child characteristics leading to issues in parental participation.

2. Background:

Parents raising children with special needs encounter many challenges in their daily lives. However, the initial studies using the LPP (Fingerhut, 2009; Fingerhut, 2012) determined that these challenges should be predicted by age, gender, or diagnosis of the child, the time the child has been in therapy, or the age, gender, or marital status of the parent. These challenges are unique to each individual and therefore an instrument is needed to assess individual parental needs to facilitate family-centered intervention. Family-centered practice in pediatric occupational therapy involves working with parents, families, and the child with special needs to facilitate participation in the therapy. Assessment in occupation (American Occupational Therapy Association [AOTA], 2008; Rosenbaum, King, Lee, King, & Evans, 1998). Occupational therapy practitioners frequently address family-centered practice as parental involvement in establishing and facilitating child-related goals (Fingerhut, 2009; Saffer, Humphrey, & Case-Smith, 2012). However, family-centered practice goals focused child-related goals to incorporate changing the quality of life for the whole family (Rosenbaum et al., 1998). Families are interdependent, and intervention with the child can have a significant impact on the participation for the entire family, especially the parents. Raising a child with special needs can influence a parent's time usage, health, and choice of activities (Trower, 1993; Jones & Pomeroy, 2005; Kahanovich, Barnagault, Wright, Lemanowicz, & Damagh, 2000; Schaefer, Tash-Cahen, Johnson, Gukian, & Rosenfield, 2011). To provide best practice family-centered intervention, therapists need to understand individual barriers to life participation for the child, parents, and other family members (Kahanovich, Spratt, Rosenfield, & Anderson, 2002; Roberts & Leckie, 2001; Rosenbaum et al., 1998).

The LPP is a 32-item self-report questionnaire using a 5-point Likert scale. Each item also has space for a qualitative comment regarding the response. It is designed to be used by clinical practitioners such as occupational therapists, physical therapists, or speech and language pathologists in determining issues parents are having in participating in their child's lives. The issues identified by the LPP can then initiate further conversations between parent and clinician and assist with developing family-centered intervention goals. The LPP was developed using an Occupational Adaptation frame of reference providing focus on both the efficiency and the effectiveness of a parent's ability to participate in life activities affected by raising a child with special needs. A preliminary pilot-scale comparison analysis revealed evidence for the test-retest (Fingerhut, 2012). The LPP takes approximately 10 minutes to complete by the parent and is scored easily by the therapist. Two other questionnaires (Infant-Toddler Sensory Profile and Child Behavior Checklist) will be used to further investigate the impact of child behaviors on parent participation. Occupational therapists treat numerous young children with sensory processing abnormalities due to developmental delays. Sensory processing is intimately intertwined to sense the process by which the brain receives and makes use of all forms (tactile, auditory, visual, etc.) of sensations to generate behavioral responses to the environment. Research shows that between 40% and 60% of children with Autism Spectrum Disorders (ASDs) and other developmental disorders present with sensory abnormalities, and sensory-related behaviors often drive referrals to occupational therapy. The majority of research in this area focuses on school-age children with ASDs. The parents of these children already increased levels of stress and disruption to family life and participation is reduced as a result. Since family members are interdependent, each member's ability to participate in occupations affects their own health and the health of the others. There is currently no research on how sensory abnormalities and sensory-driven behavior of young children (0-3 years old) affect parent participation in occupations. This is a critical factor in occupational therapy intervention for young children and their families.

3. Overview Summary of Project:

The proposed study will use a pretest - intervention - posttest longitudinal design to assess the sensitivity of the LPP to measure change. A previous study established that the responses on the LPP were stable over the short term (2-3 weeks) when there were no focused intervention between pretest and posttest (Fingerhut, 2012). At pretest, parent participation with children under the age of 3 will need to be assessed to complete the Infant-Toddler Sensory Profile (ITSP) and Child Behavior Checklist (CBCL). This information will be correlated with parent participation on the LPP to investigate the effect of these child characteristics on parent participation.

4. Study Procedures:

Occupational therapy participants will be recruited from pediatric occupational therapy clinics and early intervention programs throughout Texas. Occupational Therapists (OTs) 0-30 will be approached by the investigators to ask if parents from their current clients to complete the LPP (n=60). If these parents identify issues that the therapist believes would be amenable to family-centered intervention in a 3-month time frame the parents will be recruited into the longitudinal study. If not the therapist will continue to recruit until they recruit 2 parents. Parents with children under the age of 3 will also be asked to complete the ITSP and CBCL at this initial stage. This information will be used to investigate the effect of measured child characteristics on parental participation. The parents with children under the age of 3 may also be enrolled into the longitudinal aspect of the study depending on the issues they discuss on the LPP. Parents with children under the age of 3 will continue to be recruited until there are 50 participants.

For parents recruited to the longitudinal aspect of the study, the therapist will use the information from the LPP to further explore the responses with the parents and then collaboratively establish one family-centered goal related to an item on the LPP.

<p>The therapist will start design intervention to address the goal in addition to the established intervention he or she was providing for the child and family. The study researchers will provide information on family-centered intervention, training, and strategies to assist the therapist in providing effective family-centered intervention. Intervention will be provided for three months or until the child's therapy is discontinued. At this point (3 months or discontinuation), the parent will complete the LPP again. The therapist will complete a short survey including the goal established, the intervention provided, and the observed outcome of the intervention. Therapists will also be interviewed regarding their experience using the LPP to facilitate family-centered intervention.</p> <p>Data Analysis/ Study Questions</p> <ol style="list-style-type: none"> 1. Is there a significant positive change on the overall LPP score for these parent participants whose intervention outcome was described as positive by the therapist? (Wilcoxon signed-rank test). 2. Is there a significant positive change on the LPP items most closely related to the established goals for these parent participants whose intervention outcome was described as positive by the therapist? (Wilcoxon signed-rank test). 3. Do levels of sensory processing as measured by the Infant/Toddler Sensory Profile (ITSP) correlate with parent participation as measured by LPP? 4. Do levels of maladaptive behaviors, as measured by the Child Behavior Checklist (CBCL) correlate to levels of parent participation as measured by the LPP? 5. Does the pattern of sensory presentations as measured by the ITSP correlate with maladaptive behaviors as measured by CBCL? <p>Study data (demographics and data) from LPP completion (provided only for those in the longitudinal study) will be added to data from previous studies (N = 187 + 4000) for confirmatory principle component analysis (future revision).</p>	<p>unrelated text area</p>
<p>(k) Describe the procedures that are being or were done for diagnostic or treatment purposes.</p> <p>Parent participants will complete the LPP. Those with children under the age of 3 will also complete the ITSP and CBCL. Intervention issues will be determined by the OT currently working with the family from the responses. This OT will provide the only intervention involved in this study.</p>	<p>unrelated text area</p>
<p>(l) Describe the setting in which the research will occur.</p> <p>The data collection and intervention will occur in the setting where OT services are being delivered (clinic, home, or community setting).</p> <p>(m) Describe the processes that are set into to protect subject's privacy interests.</p> <p>Participant privacy and confidentiality will be maintained throughout the research project. Questionnaires will not be viewed by anyone beyond the treating therapist at the intervention settings. Communications between parent participants and therapists will be private as per facility requirements. Participating occupational therapists and participating parents will be given codes for the questionnaires and interviews. The data collected by the participating occupational therapists from the participating parents will be typical of that normally collected during intervention. Outside of this therapist-provider/client relationship the data will be owned by the researchers. The only connection to the coded data will be the consent forms which will be kept by the researchers separate from the data. All data will be kept in a secure locked cabinet and / or in an encrypted computer.</p>	<p>unrelated text area</p>
<p>(n) When some or all subjects are subjected to coercion or undue influence, what additional safeguards are you including to protect their rights and welfare?</p> <p>OT participants are assured in the consent letter that their relationship to the UTRB or TAPU OT programs will not be influenced by their participation or non-participation in the study. Parent participants are assured in the consent letter that access to the OT services they are receiving will not be influenced by their participation or non-participation.</p>	<p>unrelated text area</p>
<p>5. Inclusion and Exclusion Criteria:</p> <p>Number of Subjects (may refer to protocol) <input type="checkbox"/> N/A</p> <p>Total number of subjects (specific number): 35</p> <p>Total number of subjects at UTRB (specific number): 4</p> <p>Age Range 18-45</p> <p>Gender: <input checked="" type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> No</p> <p>How will you ensure equitable subject selection? Do all appropriate demographic groups have equal access? Will all appropriate demographic groups be invited to participate? If not, explain, please (OTF A/B).</p> <p>All participants who meet the inclusion criteria have access.</p> <p>Inclusion/Exclusion Criteria:</p> <p>All occupational therapists (OT) working with children with special needs at UTRB can be recruited for the study. The therapists will be provided with information about family-centered intervention and family-centered goals and will need to agree that they understand and are comfortable with using this frame of reference in their intervention.</p> <p>Any parent, contacted by the therapist as potentially having participation issues that might be effectively addressed by therapy is eligible for inclusion. For purposes of the study only the parents of identified children with special needs less than 12 years of age will be included. Only parents of children less than 3 years old will complete the ITSP and CBCL.</p> <p>Exclusion/Exclusion Criteria:</p> <p>This study is designed to address participation issues parents are struggling with that can be addressed by OT intervention in a 3-month time frame and have these characteristics:</p>	

contribute to these participation issues. If no goals can be identified from a person's initial completion of the LPI the parent will not be included in the longitudinal aspect of the study. However, if a parent's issues are so significant that there is not likely to be measurable change in 3 months the parent will not be included. If the therapist believes his or her practice setting or reimbursement is not amenable to a family-centered treatment approach, the therapist will not be included in the study. Only parents with children under 3 years will complete the ITSP and CBCL. The questionnaires and consent forms will only be available in English and Spanish.

additional text area

A. Study Population

Please indicate which, if any, of the following are selected:

Study Population 1: Adults

Study Population 2: ITM staff

Study Population 3: Other

Study Population 4

Study Population 5

Study Population 6

Study Population 7

Study Population 8

Study Population 9

Study Population 10

Note: Studies with the following choices cannot be completed:

- Products of Service Identification
- Patient Release

B. Subject Recruitment

Describe how you will recruit subjects:

☒ Direct person-to-person solicitation per consent form.

☐ If the consent form has been signed and be forwarded to a participating site, see below.¹

☐ Newspaper(s)

☐ Letter

☐ Radio

☐ Other

¹ Refer to the instructions in Section 4, "Subject Recruitment and Participation" of the ITM 349 Policy and Procedures Manual for Research.

Faculty and Staff located at www.itm349.org

If the subjects are to be recruited under B, please include an outline of the recruitment. For items c, d, and e please submit written copies (e.g., letter, notes, and advertisements). In addition, please supply web addresses, if applicable, for all advertisements and/or promotional materials.

Do you plan to use Research Match for recruitment? ☐ Yes ☒ No

Do you want the study posted on ITM's free recruitment website? ☐ Yes ☒ No

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6. Informed Consent, Parental Permission and CHM Assent

Note: Written informed consent/permission from the subject or from a legally responsible representative of the subject is strictly required from human research participants. The proposed consent form should be included with the materials submitted to the IRB.

a. Will the study require obtaining written documentation of informed consent? ☒ Yes ☐ No

b. Describe the method to be used to obtain informed consent. Prospective research ordinarily requires written informed consent. If any special circumstances exist, please explain.

The researchers will contact the occupational therapists in person to request participation in the study. Each OT will identify the parents (parent clients) who will complete the IFF or I/P, I/SR, and CBO. Therapists and parents who are willing to participate will be asked to complete the appropriate consent form.

c. Who will conduct the consent interview?

Researchers will conduct the interview for therapists. Therapists will conduct the interview for parents.

d. Who will provide consent or permission (subject, parent, legally authorized representative)?

e. Will there be a waiting period between informing the prospective subject and obtaining consent/permission? ☐ Yes ☒ No
Please explain:

If, after explanation of the study, participants verbally consent they will be immediately provided with the consent form.

f. What steps will you take to minimize the possibility of coercion or undue influence?

Therapists recruiting parent participants will be provided training in how to recruit and cautioned about jeopardizing their therapist - client relationship through coercion.

g. Please explain how the process for subject complaints, concerns or requests for information will be managed. (Please be reminded any complaints need to be reported to the IRB within 14 business days).

Please submit for the PI and Office of Research any provided in the consent letter.

h. Is there a possibility that some potential subjects whose first language is not English will wish to enroll? ☒ Yes ☐ No

i. Are you submitting a copy of the consent/parental permission form translated into their primary language? ☐ Yes ☒ No
Please explain:

j. Are you recruiting children? ☐ Yes ☒ No

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7. Confidentiality of Data/Specimens

1. Specify how confidentiality will be maintained for research data.

Participant confidentiality will be maintained throughout the research project. Participating occupational therapists and participating parents will be given codes for the questionnaire and interviews. The data collected by the participating occupational therapists from the participating parents will not be include that which may normally be collected during intervention. Outside of this provider/client relationship the data will be coded by the researchers. The only connection to the coded data will be the consent forms which will be kept by the researchers separate from the data. All data will be kept in a secure locked cabinet and / or on an encrypted computer.

2. Specify how confidentiality will be maintained for research specimens.

N/A

3. Will the specimens or data be identifiable? ☐ Yes ☒ No ☐ N/A

4. State the type of identification, direct or indirect, on any specimens or data which they are made available to your study team. (Direct: name, address, phone number, etc. Indirect: pseudonym - any number that could be used by the investigator to link groups providing the data/specimens to identify a subject, e.g., participant tracking number, medical record number, subject ID or cryptic code number)

All questionnaire data will be coded. Only the PI and Co-PI will have access to the code key.

5. How will data be protected, e.g., locked filing cabinet in investigator's office, on computer, etc?

All data will be kept in a secure locked cabinet and / or on an encrypted computer.

6. Do you or any of the members of your research team receive (or will you receive during the course of the study) personal financial compensation from the sponsor of the study, (stock, business ownership, board membership, consulting fees, etc.)? ☐ Yes ☒ No

Please explain:

7. Describe your processes to protect the privacy of the subjects.

As described above, questionnaire data will not be shared with anyone at the testing facility beyond the testing therapist. Conversations between parent participants and testing therapists will be kept private as per the facility requirements.

8. Does this activity involve data collected for other purposes? (e.g., hospital records) ☐ Yes ☒ No

9. Could any part of this activity result in the potential identification of child abuse, elderly abuse, communicable diseases, or criminal activities that would/could not have been otherwise identified? ☐ Yes ☒ No

Explain the likelihood of disclosure:

Very unlikely. The information is regarding a parent's ability to participate. Some responses may indicate emotional physical stress, depression, etc. which will be explored with the participant by the therapist. No responses are outside information regularly collected during the course of intervention.

9.A. If any testing records and identifiers are present, the consent form must state that the results will be reported to appropriate local and state agencies and childbearing officials. Does the consent form contain that? ☐ Yes ☐ No ☒ N/A

10. Describe your processes for monitoring the data to ensure safety of the research subjects.

Data is typical of that regularly collected during occupational therapy intervention. The participating OTs will safeguard the data in the manner consistent with professional ethics. The researchers will have coded data where the key is only accessible to the PI and Co-PI.

B. Risks and Benefits to the Subject and/or Society

List the risks:

The only potential risk is known to the potential loss of time for parent participant and / or occupational therapist. This risk is inherent in any intervention.

List the benefits:

Parent participants in this study should receive intervention to address participation needs that they have self-identified. Occupational therapists participating in this study will develop skills in using a data instrument that may be beneficial in their future practice. Outcomes of this study may contribute to the development of a new evidence-based instrument for

Facilitating effective Family-centered Intervention: New information may be obtained to identify child factors affecting parent participation.

6. Research Tools
Please indicate which, if any, of the following you propose to use and provide copies for IRB review:
☐ Interview Tools ☐ Educational Materials (handouts, books, etc.)
☒ Questionnaires ☐ Interview
☐ Surveys ☐ Story
(Please provide copies of these items for IRB review.)

10. Subject Reimbursement
Will subjects receive reimbursement? ☐ Yes ☒ No



Working together to work wonders™

Institutional Review Board
301 University Blvd.
Galveston, TX 77550-0158
409.266.9475

04-Dec-2014

MEMORANDUM

TO: Patricia Fingerhut, OTR, PhD
Occupational Therapy 1142

Andrea M. King

FROM: Michael Loeffelholz, PhD
Institutional Review Board, Chairman

RE: Initial Study Approval

IRB #: IRB # 14-0326

TITLE: The Life Participation for Parents (LPP) as an Outcome Measure

DOCUMENTS: Protocol, Therapist Consent Form, Parental Participant Consent Form, Child Behavior Checklist (English & Spanish), Infant Toddler Sensory Profile (English & Spanish), and LPP

The UTMB Institutional Review Board (IRB) reviewed the above-referenced research protocol via an expedited review procedure on **21-Nov-2014**. Having met all applicable requirements, the research protocol is approved for a period of 12 months. The approval period for this research protocol begins on **04-Dec-2014** and lasts until **21-Nov-2015**.

The research protocol cannot continue beyond the approval period without continuing review and approval by the IRB. In order to avoid a lapse in IRB approval, the Principal Investigator must apply for continuing review of the protocol and related documents before the expiration date. A reminder will be sent to you approximately 90 days prior to the expiration date.

The approved number of subjects to be enrolled is **90**. The IRB considers a subject to be enrolled once s/he signs a Consent Form. If, additional subjects are needed, you first must obtain permission from the IRB to increase the approved sample size.

If you have any questions related to this approval letter or about IRB policies and procedures, please telephone the IRB Office at 409-266-9475.