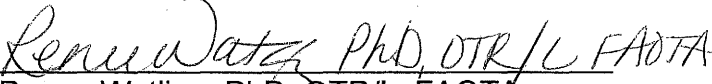


**Life Experiences of a Child with
Challenges in Sensory Processing and Integration:
A Case Study**

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This research, submitted by Andrea Johnson, OTS, has been approved and accepted in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy from the University of Puget Sound.



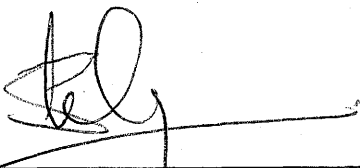
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Abstract

Children have occupations they need to perform in order to learn, grow, and develop. Challenges in processing and integrating sensory information can impair their capacities for occupational participation and engagement. Sensory integration interventions have been promoted as able to help children improve their abilities to use sensory information for function as well as provide strategies for self-regulation. Much of the research on the efficacy of sensory integration interventions is experimental and descriptive, and largely inconsistent. Qualitative methodologies have not been widely used to examine the approach or to investigate the first-person experiences of the children who participate in sensory integration interventions. This phenomenological qualitative research study investigated the life experiences of a child with challenges in sensory processing and integration who had received sensory-based occupational therapy intervention. The themes identified were *freaking out* and *I engage*. The perspectives acquired can help influence the clinical reasoning of occupational therapists and expand the research base of sensory integration interventions.

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The role of occupational therapy is to promote “the health and participation of people, organizations, and populations through engagement in occupation” (American Occupational Therapy Association [AOTA], 2008, p. 625). Participation is simply performing an activity, while engagement requires motivation and choice (AOTA, 2008). Both participation and engagement in the occupations of children can provide the foundation for learning, growth, and development.

Lane (2012) stated that “children are not little adults; they are impressionable beings who experience and learn” (p. 4). In order for children to successfully experience and learn, as well as participate and engage in occupations, they need to process, organize, and respond to sensation arising from the body and the environment. This process is called sensory integration and it is the foundation for the development of self-awareness, learning, and behavior (Ayres, 1972).

The theory of sensory integration, as conceptualized by Ayres (1972), is the “neurological process that organizes sensation from one’s own body and from the environment and makes it possible to use the body effectively within the environment” (p. 11). Ayres’ theory was developed in accordance with the neuroscience research of her day and revolved around the phenomenon of neuroplasticity, or the brain’s ability to change its structure and function in response to experience (Parham & Mailloux, 2010). A typically developing person is able to process and organize sensory information from both the body and the environment in order to create an accurate body scheme and

judge the body's orientation in space. This information allows the individual to respond to sensory experiences in an appropriate manner and adapt his or her responses to novel experiences as necessary. The brain collects and draws upon these experiences and responses for the performance of everyday childhood occupations such as self-care, education, play, leisure, and social participation. Any time the response to a sensory experience is more complex than its predecessor, organization of the brain is improved and the "capacity for further sensory integration is enhanced" (Parham & Mailloux, 2010, p. 327).

Dysfunction in processing, organizing, and integrating sensory information for use may manifest as poor gross and fine motor skills, language skills, cognition, and emotional regulation which in turn affect academic performance, occupational engagement, and participation in family and social life (Parham & Mailloux, 2010; Watling, Koenig, Davies, & Schaaf, 2011). It is estimated that 5% to 15% of American kindergarteners (Ahn, Miller, Milberger, & MacIntosh, 2004), 40% to 80% of children with developmental disabilities (Baranek et al., 2002), and 30% to 100% of children diagnosed with autism spectrum disorder (Dawson & Watling, 2000; Tomchek & Dunn, 2007) have these types of challenges in processing and integrating sensory information.

Many intervention strategies can be implemented when addressing these deficits; sensory integration being one of the most utilized approaches (Blanche & Blanche Kiefer, 2007). Occupational therapy research on the effectiveness of sensory integration interventions is mixed; nevertheless, caregivers have expressed appreciation for the changes in abilities, activities, and self-worth sensory integration interventions bring to their children (Cohn, 2001b). Expanding the research base on

sensory integration interventions is an important step in increasing the knowledge and understanding of the effects of this treatment approach. Most of the existing research on sensory integration interventions utilized experimental or descriptive methodologies. Qualitative research methodologies have the potential to provide relevant data on par with experimental, outcomes, and descriptive research (Tomlin & Borgetto, 2011). Additionally, much of the existing qualitative literature surrounding sensory integration interventions for children focuses on parental and familial perceptions (Cohn, 2001a; Cohn, 2001b; Cohn, Miller, & Tickle-Degnen, 2000) while the perceptions of the children themselves are unknown.

Background

The field of occupational therapy is concerned with an individual's ability to engage in occupations and participate in everyday life. Occupational engagement requires an individual to make choices and to be motivated to perform. Engagement includes "carrying out activities meaningful and purposeful to the individual person" (AOTA, 2008, p. 660). Participation is defined by the World Health Organization (2001) as "involvement in a life situation" (p. 10), and is the natural outcome of performing an activity (AOTA, 2008). For children, occupational engagement and participation provide the foundation and the building blocks for learning, growth, and development. When engagement and participation are disrupted, so are these outcomes.

Participation and engagement. Kids want and need to do the everyday "kid things" (Lane, 2012, p. 3) that contribute to learning, growth, and development. Learning and systems theorists have proposed a sequential developmental process whereby the everyday kid things contribute to the maturation of the central nervous system (CNS)

and result in learning (Case-Smith, Law, Missiuna, Pollock, & Stewart, 2010). They believe that a child must interact with his or her environment in order to grow in “knowledge, skills, and occupations through experience that leads to a permanent change in behavior and performance” (Case-Smith et al., 2010, p. 30). Burgman (2012) believes that everyday kid things also contribute to a sense of agency, which she describes as the “ability to self-determine engagement with and response to life experiences” (p. 11). Engagement suggests a “commitment made to performance” (AOTA, 2008, p. 660), rather than simply performing an activity. However, simply performing an activity, or participating, may provide a child with the experience necessary to determine whether or not an activity elicits enough meaning and/or purpose for the child to make that commitment to performance. The ability and desire to participate and engage in occupations that are wanted and needed contributes to the development of identity and competence, and supports health and participation (AOTA, 2008). Childhood roles of family member, friend, student, and player (Posatery Burke, Schaaf, & Lomba Hall, 2008) typically provide plenty of occupational opportunities for participation and engagement.

Areas of occupation. The American Occupational Therapy Association (AOTA, 2008) has offered multiple definitions for the term “occupation” (pp. 628-629), all of which encompass the concept of daily engagement in purposeful or meaningful activities. Occupational therapists recognize that participating and engaging in occupations can help to organize daily life and promote overall health (AOTA, 2008). Eight areas of occupation have been identified, five of which are of primary concern to

children: activities of daily living, instrumental activities of daily living, education, play, leisure, and social participation (AOTA, 2008).

Activities of daily living (ADLs) are fundamental self-care activities (AOTA, 2008) and essential occupations within the maturation process (Shepherd, 2010). Active participation in ADLs such as bathing, dressing, and grooming can help a child to progress in the development of physical skills and problem-solving skills (Shepherd, 2010). Learning and mastering ADLs can cultivate self-esteem, self-reliance, self-determination, autonomy, and pride (Shepherd, 2010). Responsibility for establishing habits and routines for ADL performance that is socially acceptable increases over time and becomes necessary for engagement in other occupations and community living (Shepherd, 2010).

Instrumental activities of daily living (IADLs) are home- or community-based activities that take place beyond the self, such as meal preparation and cleanup, care of pets or others, and community mobility (AOTA, 2008). Natural opportunities for participating and engaging in IADLs exist within the home and community for children as young as three years (e.g. assisting in caring for pets, meal preparation and cleanup, and shopping); however, the autonomy developed in adolescence seems to motivate the development of the more complex IADLs in preparation for independent community living (Loukas & Dunn, 2010). Participation and engagement in IADLs at any age or ability level can “promote self-determination, self-sufficiency, health, and social participation” (Loukas & Dunn, 2010, p. 518).

Education encompasses both formal and informal activities necessary for learning (AOTA, 2008). Children in formal educational settings (schools) can be

expected to participate and engage in academic and nonacademic activities that help them develop performance skills such as sensory/perceptual, motor, cognitive, and social (Bazyk & Case-Smith, 2010). These skills can help support participation and engagement in other occupations throughout the lifespan.

Play is one of the primary occupations of childhood (Knox, 2010; Parham, 2008; Watling et al., 2011) and often occurs throughout the majority of a child's day. AOTA (2008) categorizes play and leisure as separate occupations; however, for children play and leisure often seem to be quite similar: active engagement in spontaneous, enjoyable, amusing, intrinsically motivating, nonobligatory activities of choice (AOTA, 2008; Parham, 2008). Participation and engagement in play and leisure are natural opportunities for children to develop cognitive and physical skills (Parham, 2008), learn about the environment (Knox, 2010), and become proficient in interacting with it (Knox, 2008). "Occupational roles change across the lifespan" (Parham, 2008, p. 21), and the skills gained in childhood through play are likely to support participation and engagement in increasingly challenging occupations later in life.

Social participation involves utilizing patterns of behavior expected within community, family, and peer/friend contexts (AOTA, 2008). In Western cultures, school is an additional social context for children (Olson, 2010). Many friendships originate from the peer interaction and social acceptance that occurs in these contexts, and can encourage emotional security, positive self-esteem, and social support (Olson, 2010) as well as foster resilience (Burgman, 2012). "Friendship can support adaptive social processing skills including perspective taking and the development of social skills important for interacting in many social environments" (Olson, 2010, p. 312). Friendship,

therefore, may lead to successful participation and engagement in activities with other individuals, community members or organizations, obligatory or chosen roles, and intimate relationships (AOTA, 2008).

The influence of sensation.

Sensation as a foundation for learning, growth, and development. For some children, engagement and participation in these areas of occupation are hindered by challenges in processing and integrating sensory information. Introduced by A. Jean Ayres more than 40 years ago, the theory of sensory integration focuses on “the organization of sensation for use” (Ayres, 1979, p. 5) and was intended to “explain the relationship between deficits in interpreting sensation from the body and the environment and difficulties with academic or motor learning” (Bundy & Murray, 1991, p. 3). Occupational therapists use this theory to help understand how a child’s learning, growth, and development are impacted by the sensations experienced in everyday life, and to plan intervention and predict change (Bundy & Murray, 1991).

The sensory integration theory delineates the role of sensation in supporting growth and achievement of typical developmental milestones in children. Sensory information comes from seven distinct systems: visual, gustatory, olfactory, auditory, tactile, vestibular, and proprioceptive. Sensory information travels through each of these systems to diffuse areas of the central nervous system, where it affects the functions and structures that are active in processing and integrating sensory information. Sensory input is used in a variety of ways, including but not limited to an individual's ability to modulate his or her response to a stimulus based on its intensity and duration, discriminate among temporal and spatial characteristics of a stimulus, control ocular

movements, maintain antigravity positions and balance, use both sides of the body together, sequence an activity, and conceptualize, plan, and perform motor actions (Anzalone & Lane, 2012; Schaaf et al., 2010). All of these functions serve as building blocks for the development of advanced and complex skills needed as a child grows.

Two of the primary concepts Ayres developed her theory around are neuroplasticity and the adaptive response. Neuroplasticity is the ability of the brain to alter its structure and function in response to experiences (Parham & Mailloux, 2010). As a child engages in activities and participates in daily life, input is received through the sensory systems. As that input is processed and integrated it affects the nervous system structures and functions involved in the processing. Each experience a child has builds on previous experiences, which in turn promotes dendritic branching, creates new synaptic connections, and increases brain tissue mass (Parham & Mailloux, 2010). All of this neural activity interacts to help the child develop a repertoire of appropriate and effective responses for a wide variety of sensory information (Parham & Mailloux, 2010).

The adaptive response described by Ayres is a reflection of the individual's ability to respond to an environmental situation in an appropriate manner (Ayres, 1979). Throughout the day, sensations from the environment and the child's body are received by the nervous system where they are organized and processed, and where a response to those sensations is generated. A response that is adaptive to the incoming sensory information "allows the individual to adjust the nature, timing, and intensity of their response in accordance with the characteristics of the situation or stimulus being encountered" (R. Watling, personal communication, 7/28/2012). Adaptive responses are

dependent on good sensory processing and integration, and serve as building blocks for the skills needed for more complex and mature development, occupational engagement and participation.

Dysfunction. From the perspective of sensory integration theory, dysfunction occurs when an individual has challenges in processing and integrating sensory information (Watling et al., 2011), which can limit an individual's occupational participation and engagement. For a child with challenges in processing and integrating sensory information, the performance of ADLs, play and leisure activities, academic pursuits, and social interactions can be diminished (Watling et al., 2011). Children may display challenges in praxis; postural control, bilateral integration, and sequencing; modulating sensory input, including gravitational insecurity and aversive responses to movement; and/or tactile dysfunction including challenges in sensory discrimination and sensory defensiveness (Bundy & Murray, 1991; Watling et al., 2011). These challenges may occur in clusters (Watling et al, 2011) and can impede participation and engagement by influencing occupational choices (Dunn, 2001) and hindering daily routines (Schaaf et al., 2010). The child may be less likely or unable to participate and engage in self-care, academics, or social situations due to the distractibility, avoidance, or somatosensory deficits often resulting from challenges in sensory processing and integration (Schaaf et al, 2010).

Dunn (2009) suggested that occupational therapists must understand "how [people's] nervous systems are receiving, processing, and making meaning out of the sensory information that is available to them" (p. 777) before they can understand people's lived experiences. Her discussion (2009) of sensory processing emphasizes

the transformation of the stimulus from an electrical impulse into a meaningful experience to be organized and used to formulate a response. Dunn proposes four patterns of behavior that she purports correspond to the individual's neural thresholds and self-regulation strategies: sensation seeking, sensation avoiding, sensory sensitivity, and low registration. Dunn argues that all of these characteristics are present, along continuums, in every person and that when a characteristic exists at an extreme, behavior and occupational performance are impacted (Dunn, 2009).

Concepts for intervention. A variety of intervention strategies exist that are based on the influence of sensation on purposeful behavior and function. Among these are two primary approaches to intervention for challenges in processing and integrating sensory information: the well-defined approach called Ayres Sensory Integration Intervention (ASI[®]) and a collection of individual methods and strategies collectively referred to as sensory-based interventions (Watling et al, 2011).

The focus of ASI[®] is to increase the nervous system's effectiveness at using sensory information in order to produce adaptive responses and promote praxis (Watling et al., 2011). It is a bottom-up approach, seeking to remediate underlying deficits in general sensory processing and integration abilities by focusing primarily on the proprioceptive, vestibular, and tactile systems. This is achieved by introducing activities suitable for the child's current level of function and gradually increasing an activity's difficulty with an emphasis on supporting the child's ability to produce adaptive responses (Watling et al., 2011). To accurately be identified as ASI[®], strict adherence to 10 core elements (Parham et al. 2007) is necessary: provide a range of sensory opportunities; provide activities with the just-right challenge; collaborate with the client

on activity choice; guide self-organization; support optimal arousal; create play context; maximize child's success; ensure physical safety; arrange the physical environment to engage child; and foster therapeutic alliance. Each of these is further described in the publication by Parham et al. (2007). ASI[®] interventions are a 1-to-1, individualized experience, involving active participation by the child and typically employing proprioceptive, vestibular, and tactile activities in a specialized environment (Schaaf et al., 2010).

In contrast, sensory-based interventions take on various forms and approaches, and none of them conform to the ten core elements of ASI[®]. The target outcomes of sensory-based intervention are similar to those of ASI[®]; however, the sensory-based interventions focus on remediating specific sensory issues and their accompanying maladaptive behaviors rather than improving the underlying sensory processing and integration (Watling et al., 2011). Focusing on more immediate, specific concerns makes sensory-based interventions top-down approaches. As a result, intervention may take place outside the clinic in interdisciplinary-led groups at school and parent-monitored activities at home (Watling et al., 2011). Children may be provided sensory opportunities (e.g. touching a variety of materials, crashing onto padded surfaces, and swinging [Schaaf et al., 2010]), as well as self-regulation training (e.g., the Alert Program for Self-Regulation: How Does Your Engine Run?, Williams & Shellenberger, 1994) and sensory diets (Wilbarger & Wilbarger, 2002), which provide strategies designed to help a child self-regulate how they respond to sensory experiences within their daily lives.

Evidence for sensory integration intervention. Four studies and two meta-analyses evaluating the efficacy of sensory integration interventions are frequently referenced in scholarly articles discussing sensory integration (e.g., Arendt, MacLean, & Baumeister, 1988; Hoehn & Baumeister, 1994; Ottenbacher, 1982; Polatajko, Kaplan, & Wilson, 1992; Schaffer, 1984; Vargas & Camilli, 1999). The contrasting findings in these studies preclude consensus about the literature to date. Schaaf and Davies (2010) suggested that the reasons for inconsistent evidence on the effectiveness of sensory integration interventions may be due to concept evolution within the theory of sensory integration (Miller, Anzalone, Lane, Cermak, & Osten, 2007) and differences in the way various related terms are used (Miller & Lane, 2000). Operational definitions of sensory integration interventions, heterogeneity of subjects and outcome measures, a lack of manualization, small sample sizes, and less rigorous methodology in studies included in evidence-based reviews have been implicated as well (Arbesman & Lieberman, 2010; May-Benson & Koomar, 2010; Miller, Coll, & Schoen, 2007; Miller, Schoen, James, & Schaaf, 2007; Parham et al., 2007; Polatajko & Cantin, 2010). Despite these concerns, the literature has shown support for the approach with positive effects in the areas of children's abilities, activity participation, and feelings of self-worth (Cohn, 2001b). Sensory integration intervention methods are widely used in occupational therapy intervention (Watling et al., 2011); therefore, it is important to continue examining the usefulness of this approach.

Qualitative inquiry. May-Benson and Koomar (2010), in their systematic review of sensory-based intervention efficacy studies, proposed that outcomes research need

not be based solely on the significance of statistics generated in quantitative studies.

They stated,

Statistical significance indicates only that a given result is likely to not occur by chance, whereas effect sizes reflect the magnitude of the clinical effect; thus, examination of the effects of an outcome is likely to yield more clinically relevant information for the occupational therapy practitioner (p. 411).

Historically, professions concerned with methods to modify human behavior and performance have considered systematic reviews, meta-analyses, and randomized controlled trials to be the gold standard of empirical evidence and has placed qualitative methods at the bottom of the levels of evidence hierarchy or neglected to include them at all (Tomlin & Borgetto, 2011). However, a recent recommendation for restructuring the levels of evidence suggests that qualitative studies can be just as valuable as experimental, outcomes, or descriptive research in providing evidence for occupational therapy decision-making (Tomlin & Borgetto, 2011).

A survey of 199 occupational therapists conducted by Hinojosa, Sproat, Mankhetwit, and Anderson (2002) found that 30% of the time pediatric occupational therapists spent with their clients' parents was devoted to addressing concerns, feelings, and needs. Cohn et al. (2000) identified categories for these concerns, feelings, and needs through qualitative interviews of parents of children with sensory modulation disorders. They discovered that parents had expectations for therapy which revolved around both the child and themselves. Improvements in social participation, self-regulation, and perceived competence were what parents wished for their children; new support strategies and personal validation were what parents wished for themselves.

Similar themes were uncovered when Cohn (2001b) conducted qualitative interviews of parents of children who had completed sensory integration interventions. The outcomes recognized by parents again fell into the categories of child-focused and parent-focused. Children had increased their abilities, activity participation, and feelings of self-worth. Parents had acquired the validation and support strategies they desired. They also acquired a deepened understanding and a change in expectations for their children and themselves. One additional outcome of sensory integration interventions for children with challenges in processing and integrating sensory information discovered by Cohn (2001a) was the waiting room phenomenon, in which caregivers perceived benefits from interacting with other caregivers while seated in the pediatric clinic waiting room. This outcome arose from Cohn's 2001(b) qualitative interviews and is data that was unlikely to have been detected through experimental research.

Cohn and Cermak (1998) suggested that qualitative research can "help us understand what matters to our consumers, what they value, and what their perceptions of therapy outcomes are" (p. 545). In pediatric practice, parents are also considered to be consumers (Kanny et. al., 1995), because children may not be capable of understanding their needs or making them known (Coster, 1998). This belief likely accounts for the abundance of caregiver perspectives in pediatric occupational therapy literature, both international and domestic.

While the child perspective has rarely been addressed in the occupational therapy literature, it is now beginning to emerge. Research addressing juvenile idiopathic arthritis and home programs (De Monte, Rodger, Jones, & Broderick, 2009), quality of life of adolescents with cerebral palsy (Shikako-Thomas et al., 2009), and

assessment development for children with spinal cord injuries (Mulcahey et al., 2010) expand the child perspective on occupational therapy topics in general. To date, there is no published account of child perspective of ASI[®] or sensory-based interventions in particular. Therefore, the purpose of this study is to uncover the lived experiences of children with challenges in sensory processing and integration who have received sensory-based occupational therapy intervention.

Method

Research Design

Qualitative interviews with a Hermeneutical phenomenological methodology (Groenewald, 2004; Vandermause & Fleming, 2011) were conducted in order to examine the target phenomenon. Qualitative research is naturalistic, open-ended empirical inquiry. Phenomenological research seeks to describe the meaning behind life experiences from a subjective, first-person perspective (Denzin & Lincoln, 1998). Hermeneutical phenomenological research emphasizes the bracketing, or setting aside, of the researcher's biases (Groenewald, 2004). Phenomenology lends itself naturally to research in the field of occupational therapy because understanding a client's condition holistically (AOTA, 2008) from his or her point of view can influence the therapist's clinical reasoning and selection of intervention approaches. Phenomenology also lends itself naturally to interviewing children, as it allows a child to tell his or her story in his or her own language, which may not yet be overlaid with society's language.

Procedures

A research journal was begun on December 9th, 2011, for the purpose of recording research biases, field notes, and reflections on the research process. This

was the first step in an audit trail intended to enhance validity and rigor (Krefting, 1991; Pringle, Drummond, McLafferty, & Hendry, 2011). The initial proposal for this study was reviewed and authorized by the University of Puget Sound Institutional Review Board (IRB) and the recruitment process began.

Three children who had received sensory-based occupational therapy for challenges with processing and integrating sensory information were initially sought for triangulation of data and to increase the likelihood of transferability of findings. Triangulation involves the use of at least three participants to contrast or validate data (Groenewald, 2004) and was the second step to enhancing validity and rigor in this study. The treating therapist at an urban pediatric occupational therapy outpatient clinic in the Pacific Northwest identified 24 clients that met the inclusion and exclusion criteria. Inclusion criteria for prospective child participants consisted of: (a) primary diagnosis of attention deficit hyperactivity disorder, attachment disorder, global developmental delay, dyspraxia, or motor incoordination; (b) specific sensory deficits including any or all of the following: somatosensory processing, modulation, motor planning, postural control, proximal stability, and fine motor skills; gravitational insecurity; anxiety; impulsivity; poor social skills, play skills, self-help skills, transitions, community participation, or mental flexibility; excessive outbursts; aggressive behavior; or problems with cognition, visual-motor and visual-perceptual skills, or self-regulation; (c) discharged from treatment prior to interview; (d) ability to tolerate the interview experience; and (e) aged 8 to 12 years as of April 1, 2012. Exclusion criteria were limited insight (as determined by the treating therapist) and primary diagnosis of Tourette's syndrome, obsessive compulsive disorder, anxiety disorder, pervasive developmental disorder, autism spectrum

disorders, or fragile X. These diagnoses were excluded as the non-sensory impairments involved with these conditions would likely have increased the heterogeneity of the sample and decreased transferability of the results (Cohn, 2001b). The clinic receptionist typed, affixed address labels to, and mailed 24 sealed, pre-stamped envelopes containing a recruitment flyer, parental consent form, and demographic questionnaire (see Appendices A, B, and C) developed and written by this researcher.

Only one family responded to the initial recruitment mailing and agreed to participate. Parental informed consent and demographic information were secured and the child interview was scheduled over the phone. During the phone conversation, the consenting parent was also asked to provide examples of the child's coping style and signs of distress. After the interview had been scheduled and before the interview took place, one mock interview was conducted with a different child who met the inclusion criteria in order to test questions and improve interviewer skill.

The initial recruitment period lasted four weeks, and the first child interview occurred during that time. When no other families responded, a modification to send a follow-up recruitment mailing was filed with and approved by the IRB. A second recruitment packet for the remaining 23 prospective participants containing a reminder letter (see Appendix D) and the parental consent and demographic questionnaire were again hand addressed and mailed by the clinic receptionist. No additional responses were received. As a result, the study design was modified. Participant definitions were changed to include the parent and treating occupational therapist of the child already enrolled in the study in order to maintain triangulation of data. This modification was filed with and approved by the IRB. One parent and the treating occupational therapist

of the initial child participant were subsequently recruited via telephone and email, respectively. They both consented and their interviews occurred within one week of recruitment.

All participants provided informed consent/assent (see Appendices E, F, and G) and received a \$15 gift card as a thank you for participating. Interviews were audio recorded and professionally transcribed, verbatim. Recordings were reviewed repeatedly while awaiting transcriptions. Notations were made during each listening opportunity.

Initial codes and themes developed by this researcher were peer reviewed by two occupational therapists specializing in pediatric practice. Peer review (Denzin & Lincoln, 1998) occurs when an indirectly involved peer reviews the data with skepticism, ultimately challenging or supporting the researcher's interpretation. This process was the third step to enhancing validity and rigor in this study. The resulting themes were member checked, a process in which the themes were reviewed and confirmed by each participant. This was the fourth step to enhancing validity and rigor in this study.

Participants

Participants were given the opportunity to select pseudonyms for the sake of quoting their responses within the manuscript. These pseudonyms are used in the following discussion.

Caroline. Caroline is a 10-year-old white female who was identified as having challenges with sensory processing, self-help, and coping skills. She resides in an urban neighborhood with two adoptive parents, both educated at the master's level, and three adoptive siblings who all speak English. Caroline was exposed prenatally to

methamphetamines, and her biological mother is suspected of having a learning disorder. She was adopted at 21 months of age. At the age of eight she was referred to occupational therapy, where she participated in sensory based interventions twice per week for 20 months. Sensory-based group activities occurred on occasion with one sibling throughout intervention and with other clinic clients in a social group during the month prior to discharge. She participated in vision therapy concurrent with occupational therapy. She participated in private counseling before occupational therapy and was still a client at the time of the interview. She currently attends the fifth grade at a public school with typically developing peers and receives resource room assistance for academics.

Eleanor. Eleanor is a 38-year-old white female and one of Caroline's two adoptive mothers. She holds a master's degree in special education, but was employed only one school year before deciding to become a stay-at-home parent and adopting Caroline. Eleanor has not received any special training regarding Caroline's challenges and does not believe that her master's education prepared her for Caroline's challenges. She does believe her master's education helped her navigate the process of seeking school-based special education services for Caroline.

Mary. Mary is a 36-year-old white female who is a registered and licensed pediatric occupational therapist in a private urban clinic. She holds both bachelor of science and master of science degrees in occupational therapy from accredited universities. Pediatric fieldwork was conducted at Georgetown University Child Development Center in Washington DC, and clinical experience has been gained through work in private clinics, public and private schools, out-patient hospitals, home-

The fact that the child participant met the inclusion/exclusion criteria and was the only prospective participant to respond during the recruitment process was due to chance.

Defining units of meaning, the second guideline, consisted of the collection of “persistent words, phrases, or themes within the data” (Morse & Field, 1995, p. 132). Repetitive words, keywords in a context, metaphors and analogies, and causal connections (because, since, etc) were identified and listed separately for each participant upon each listening of the recordings and read-through of the transcripts.

Creating clusters of units of meaning or developing themes, the third guideline, was the judgment of the researcher with regard to how each unit of meaning related or did not relate to the others. These clusters were developed manually by cutting apart printed lists of meaningful data and physically organizing them into as many as 14 similar categories, initially.

Summarizing, validating, and modifying interviews, the fourth guideline and also called member checking, was conducted by revisiting the participants in order to conclude whether or not the interpretations of the lived experiences were accurate. Only the parent and therapist were consulted for this study.

Creating a composite summary, the fifth guideline, was completed once all research data had been collected and peer review was completed. The two themes that emerged from the child interview were compared against the responses of the parent and the therapist, which were used to corroborate the child’s statements and insights.

Findings

The three participants were asked to describe aspects of Caroline’s life before, during, and after participation in sensory-based occupational therapy. Both mother and

daughter related many of the same experiences and emotions, while Mary provided an outsider perspective. Caroline was afraid for her personal safety much of the time, and her perceived need to protect herself dictated her ability to participate and engage in occupations at home, at school, and within the community. After 20 months of sensory-based occupational therapy, Caroline is still afraid and feels the need to protect herself on occasion; however, fear and self-preservation hamper her occupational participation and engagement much less than they had previously. Analysis of the life experiences recounted by Caroline, Eleanor, and Mary led to the themes *freaking out* and *I engage*.

Freaking Out

Caroline used the terms “scared,” “I didn’t know,” “I wanted to go [flee],” “freaking out,” “screwed me up,” and “creepy” a combined 16 times when referring to her perceptions of interactions with people and the environment. She described “freaking out” as being aggressive, avoiding or fleeing a situation or sensation, and “shutting down” or freezing under stress. Firsthand experience with Caroline’s “freaking out” led both her mother and her therapist to label her reactions as fight or flight responses.

Eleanor reported that Caroline’s challenges with sensory processing and integration became apparent around age four, when Caroline would “have rages” and “throw stuff” if she was unable to control a situation. Caroline expressed that early participation in sports and leisure was “hard” and that she eventually “gave up” on some of the activities. Eleanor recalled that Caroline’s instructors’ expectations and attempts to passively move her often clashed with her sensory processing and integration challenges. Caroline revealed that her sensory-based behaviors often had consequences, especially at school where her teachers believed her behaviors to be

willful. She perceived being in trouble much of the time and therefore limited her classroom participation and engagement. Caroline also revealed that she didn't have many friends and she spent much of her time being "gloomy." Eleanor recalled a nearly 18 month period when her daughter had not been invited to any birthday parties.

At the age of 8, Caroline was identified as having a vision problem. Eleanor recalled Caroline's anxiety over being touched and examined by a developmental ophthalmologist, who interpreted Caroline's anxiety as a potential sensory processing disorder. Caroline was referred to outpatient occupational therapy, and her initial experience epitomized her fight or flight tendency. "When I came in [for evaluation], I was really scared and wanted to go right then...once I walked in the door I wanted to go...I didn't know anyone. I didn't know what was going to happen. And I was just freaking out." Eleanor recalled, "Mary freaked Caroline out so badly [testing protective extension]...Caroline felt completely betrayed." Eleanor said Caroline then threw something at Mary before storming off to a corner and staying put. Mary recalled, "There was nothing I could do after that to make her feel safe here...she was startled." Mary vividly remembered Caroline as being "defensive", "hyper vigilant", and "like a deer in headlights" during their first session together, when Mary also learned that Caroline had some handwriting concerns and a very limited diet.

I Engage

Caroline did not resolve all of her sensory issues through sensory-based intervention; however, fight or flight is no longer her default response to perceived threats to personal safety. New strategies have afforded Caroline more success at

occupational participation and engagement, while other less successful strategies persist.

New strategies for success. When asked about her experiences with sensory-based intervention, Caroline revealed, "Once I was going for a couple months...I got really attached to that place." She identified the Wii and suspended equipment obstacle courses as her favorite activities. Caroline and Mary both recalled negotiating and working together on the two-player activities of the Wii game *Active Life: Outdoor Challenge*[™]. Caroline giggled as she described the jumping, diving, crashing, and client-therapist interactions involved in a "car wash" obstacle course.

Mary recalled collaborating with Caroline on self-regulation strategies based on the Alert Program (Williams and Shellenberger, 1996) and social thinking concepts. Utilizing her new self-regulation strategies, Caroline has increased her circle of friends and attended two birthday parties this year. Eleanor has noticed the difference in Caroline's social life as well as her personal relationships within the family unit, stating that Caroline has "really stepped up to the big sister role. She is able to be with the little kids and not be competitive." Caroline says she still has some challenges with participating and engaging in the classroom, but is more involved in sports and leisure activities.

Self-awareness and self-advocacy are additional strategies Caroline learned during sensory-based intervention. When faced with a challenging sensory situation, Caroline said she is able to weigh her options and find a compromise in order to participate or engage in the activity at hand. Caroline can also use these strategies during an injury or medical emergency. Eleanor shared that she is impressed by her

daughter's self-awareness and self-advocacy, and is confident that Caroline "will be fine [on an upcoming class trip], because she can speak up for herself when stuff doesn't work for her."

Less successful strategies persist. Caroline has learned many strategies for addressing her sensory processing and integration challenges, but a few areas are still met with resistance. For example, Mary and Caroline attempted to explore what Eleanor calls "food intolerances," but when the time came, Caroline resisted. Eleanor asserted that there are "certain things I can do as a parent" to help Caroline modify her eating strategies, but conceded, "[Caroline] is not going to choose to work on it until it becomes a big enough issue to her...someday it will be."

Discussion

This research project sought to discover the lived experiences of a child with challenges in sensory processing and integration who had received sensory-based occupational therapy. This researcher had expected to learn about specific challenges Caroline experienced within the contexts of home, school, and social life. What was discovered was Caroline's overarching challenge in occupational participation and engagement.

Participation and Engagement

Before sensory-based intervention, Caroline struggled with participating and engaging in many of the everyday "kid things" (Lane, 2012, p. 3) necessary for her learning, growth, and development. Maturation of her CNS was possibly constrained because she was not experiencing enough of the environment to allow for change in her behavior or performance (Case-Smith et al., 2010, p. 30). It is also possible that the

development of her sense of agency (Burgman, 2012) had stalled, as Caroline had trouble simply performing many activities which made it difficult for her to gain enough experience with them to help determine whether or not they held any meaning for her.

Mary revealed that Caroline initially presented as severely sensory defensive with a “strong aversion to just about anything” and recalled that “she refused a lot...tactilely, gravitationally, oral-motor.” Mary also noted that Caroline specifically refused bilateral coordination activities and recognized a difference in the “quality of her movements...[and] the reaction she had following them.” Mary’s impression of Caroline’s sensory processing and integration challenges was that they were “really limiting all areas of her life and also impacting, I think, her mental health, as well.”

After sensory-based intervention, Caroline was less likely to fight, flee, or freeze under stress and more likely to utilize self-awareness, self-regulation, and self-advocacy strategies to confront her sensory processing and integration challenges more adaptively. Caroline’s new strategies probably influenced her fondness for the car wash obstacle course, which had evolved over time to include unexpected movements. Success with the car wash likely gave Caroline the confidence to take more risks and try more activities, potentially contributing to her improved occupational participation and engagement across many contexts and environments. The willingness to take more risks was recognized by parents as an outcome of interventions following a sensory integration frame of reference (Cohn, 2001b). The ability and desire to participate and engage in occupations that are wanted and needed contributes to an individual’s development of identity and competence, and supports health and participation (AOTA, 2008). Thus, taking more risks might also lead Caroline to amend her sense of agency

(Burgman, 2012) by gaining more experience with and finding meaning in new activities and occupations, and developing a sense of self-determination.

Areas of Occupation

Self-awareness, self-regulation, and self-advocacy strategies have begun to help Caroline address the sensory processing and integration challenges that impact her childhood occupations. Eleanor reflected on a situation before sensory-based intervention when Caroline refused to swallow pills which led the family to seek professional help. The situation culminated in a two hour standoff between four physicians and a child. “[Caroline was] already terrified, so how was [threatening her] going to help?...Both of us kind of had that leap of, yeah, a scare tactic is not going to work on a kid who is completely terrified.” After “pragmatic practice” with M&Ms during sensory-based intervention Caroline was recently able to swallow medication in pill form when it became necessary. Eleanor recognized an emerging sense of competence and self-reliance in her daughter. “[Caroline] knew she could do it because she had done it before.” In qualitative studies about sensory integration interventions, parents of children with challenges in processing and integrating sensory information hoped for perceived competence (Cohn et al., 2000) and recognized changes in self-worth related to competence (Cohn, 2001b).

Despite progress with swallowing pills, Caroline has many “food intolerances” and associated behaviors that continue to be problematic. Mary believes Caroline’s sensory defensiveness is the root cause. “I think she just thought it tasted disgusting...I suspect it just [doesn’t] feel right in her mouth.” Mary attempted to engage Caroline in eating through cooking tasks of Caroline’s choice, but “it just didn’t seem to be what she

was ready for yet.” After sensory-based intervention, not much has changed in terms of Caroline’s food preferences; however, “freaking out” is less likely to occur around eating. Shepherd (2010) believed that learning and mastering ADLs cultivated self-esteem, self-reliance, self-determination, autonomy, and pride. Caroline’s improved self-awareness, self-determination, and a renewed desire for social participation might be responsible for her family’s ability to question her eating habits, illustrate how they have left her without energy, and persuade her to eat something in order to continue engaging in her activity.

Overstimulation in the classroom may have previously jeopardized Caroline’s education. Eleanor recalled that as Caroline advanced in school, “the need to pay attention became much more important [because] there was information that was being given out in a whole group setting.” Academic and nonacademic activities at school help children develop sensory/perceptual, motor, cognitive, and social skills (Bazyk & Case-Smith, 2010), so children need to actively participate and engage in order to learn. The level of individual arousal where learning can best occur is called the “optimal level” (Watling et al., 2011, p. 34). When Caroline’s arousal was beyond optimal—what Caroline described as “shutting down”—she was probably unable to determine which stimuli actually warranted attention at that time. The behaviors Caroline demonstrated when she shut down often resulted in disciplinary action or missed learning opportunities. After introducing Caroline to self-regulation strategies from the Alert Program (Williams and Shellenberger, 1996), Mary believed that Caroline could accurately recognize her arousal level and implement strategies to make necessary transitions. “If you [suggest]...that she might need a tool to self-regulate, she would

accept it." Mary's report of Caroline's ability to self-regulate her behavior suggests that children participating in sensory-based intervention can acquire the coping skills parents reported hoping their children would develop (Cohn et al., 2000). Caroline says she is able to achieve an optimal level of arousal for classroom participation and engagement by using her preferred mouth tool: a non-candy object resembling a "sponge that is attached to a Popsicle stick...you brush it on your tongue." Caroline might be able to use this strategy and her self-advocacy skills to help her teachers understand that her previous patterns of behavior were not willful.

Play and leisure were likely hindered by Caroline's sensory processing and integration challenges coupled with her predisposition for "freaking out" in overwhelming situations. Mary offered, "I think it makes it harder for people to like her...if she is always bossing and never accepting anybody else's ideas." Mary recognized that social thinking concepts could be layered upon Caroline's new self-regulation strategies to help expand and enhance her play and leisure opportunities. Caroline reported that she has developed a regular play routine during recess and has participated more in leisure activities, such as soccer and circus arts. Increased participation and engagement in play and leisure may provide Caroline with a variety of opportunities to develop and become proficient with skills necessary for interacting with her environment (Knox, 2008; Knox, 2010; Parham, 2008) and create additional adaptive responses (Parham & Mailloux, 2010).

Social participation involves behavioral expectations that can facilitate friendship development (Olson, 2010) and lead to more successful participation with other individuals or organizations (AOTA, 2008). Caroline explained that her new self-

regulation strategies have allowed her to participate in activities with peers before asking “if I can be a friend, and they say yes because I engaged in a game with them and then I asked.” Caroline reveled in her improved social participation with a story about a successful sleep-over party at a friend’s home where the friend’s mother surprisingly offered to “[host] my slumber party, if I am having one, at her house.” Caroline also was able to implement self-awareness, self-regulation, and self-advocacy strategies in order to behave in a manner “expected of an individual...within a social system” (AOTA, 2008, p. 633) while dealing with an injury and a medical emergency. Eleanor related the time when Caroline was hit in the face with a soccer ball. Caroline accepted the option to leave the game, but “she was able to calm down and she actually chose to go back in and continue to play.” Eleanor also reflected on the time that Caroline fell and damaged her front teeth and immediately attempted to “do kind of all the techniques she had learned to keep herself calm.” At the hospital and the dentist, Caroline was able to help her mother inform the medical staff of her challenges with sensory processing and utilize a computer and an iPod to calm and distract herself. Caroline’s success with self-regulation in these situations suggests that she is developing the emotional security and self-esteem that can result from social participation and friendship (Olson, 2010) and support participation and engagement in the occupations of childhood.

The Influence of Sensation

Mary reported that during the evaluation Caroline “very much wanted to be in control of everything. [She] wasn’t really open to new ideas, new activities, cooperation, negotiation.” Also, her reaction to being startled “did not match what typically should

happen.” Ayres’ (1972) theory of sensory integration helped Mary to recognize the sensory defensiveness and bilateral coordination challenges that were affecting Caroline’s learning, growth, and development. Caroline’s patterns of behavior might be categorized as “sensory avoiding” using Dunn’s (2009, p. 789) sensory processing concepts, as Caroline appeared to have a low sensory threshold coupled with an active self-regulation strategy. The sensory avoiding strategy seemed to be effective in helping Caroline control her environment but ineffective for her learning, growth, and development.

Caroline’s “freaking out” behaviors of aggression and withdrawal suggested that she perceived much of her daily sensory input as threats to her survival. These behaviors likely were responses intended to minimize her exposure to “new or unexpected sensory experiences” (Dunn, 2009, p. 789). According to Marieb (2005), the fight or flight response is the body’s instinctual, physiological reaction to a perceived threat to survival, and its’ cascade of involuntary events within the sympathetic division of the autonomic nervous system results in increased muscle tension and hyper arousal (Marieb, 2005). It is possible that Caroline’s challenges in sensory processing and integration caused her to be hyper aroused for extended periods of time due to her instinctual physiological responses.

Caroline also described “shutting down” or freezing in place when overwhelmed by sensory information or activity demands. If aggression or retreat are not practical (University of Texas Counseling and Mental Health Center, 2012), a person who freezes may use the moment to reflect upon past experience in order to weigh their options or develop a new strategy for handling the current crisis. For Caroline, freezing

more likely resulted from an inability to reflect and strategize because she had few to no adaptive responses for handling situations beyond her control. “Freaking out” and “shutting down” likely caused Caroline difficulty in overcoming her fears and engaging successfully with her family, peers, and the community at large.

Mary’s professional clinical reasoning led her to believe that sensory-based intervention would be beneficial for Caroline. The concept of neuroplasticity (Parham & Mailloux, 2010) allowed Mary to predict areas in which she might expect Caroline to change and to plan Caroline’s intervention (Bundy & Murray, 1991). Mary understood that increasing the nervous system’s effectiveness at using sensory information (Watling et al., 2011) and focusing on remediating specific sensory issues and their accompanying maladaptive behaviors (Watling et al., 2011) could help Caroline reach what Mary labeled the “ultimate goal” of feeling “more comfortable in her body.” Mary believed that feeling more comfortable “could really help her manage friendships and family life and school.” Therefore, the therapeutic process was a mix of bottom-up and top-down approaches.

Chronic illness and disability can cause a person to reformulate his or her self-concept and life plans and reconstruct his or her life history (Frank, 1996). Although Frank was referring to people who had acquired an illness or disability, those who are born with disabilities likely face a similar process. Before participating in sensory-based occupational therapy, Caroline’s self-concept was impaired and her primary life plan was to survive the day. Fight or flight seemed her default mechanism for survival, which was repeatedly shown to be maladaptive for occupational participation and engagement in all areas of her life. After participating in sensory-based intervention, Caroline is now

equipped with self-awareness, self-regulation, and self-advocacy strategies that can help her begin to reconstruct her self-concept and life plans (Frank, 1996). Reflecting upon the intervention experience, Mary remarked, "I didn't resolve a lot of her sensory issues, but I thought we got them to a functional place." Reflecting upon the intervention experience, Caroline pronounced, "I improved a lot" and said "yeah, I am awesome."

Sensory-based intervention also helped Eleanor to understand that Caroline's motivating force was most likely fear. Mary explained, "I think I gave [Eleanor] a new perspective on Caroline," meaning that she helped Eleanor to realize that Caroline's behavior was not willful. She wasn't being "naughty" and she wasn't trying to "misbehave or be oppositional." Now, for most of her sensory challenges, Caroline is less likely to fight, flee, or freeze. Instead, she is more likely to pause for a moment to reflect on past experience, weigh her options, and strategize or compromise. Caroline is finally developing a repertoire of adaptive responses that can help her improve her occupational participation and engagement. Amy shared that her daughter feels safer in her environments, is easier to deal with, and is more willing to abide. "She is a lot more adaptable."

Implications for Practice

Sensory-based occupational therapy intervention did not cure Caroline; however, it did help Caroline achieve and perceive improvement in her daily participation and engagement in the necessary occupations of childhood. The outcomes Caroline described were consistent with outcomes hoped for (Cohn et al., 2000) and valued (Cohn, 2001b) by parents of children with challenges in sensory processing and integration. This suggests that children as young as 10 years might be capable of

acquiring and articulating accurate and helpful insights about their sensory processing and integration challenges and sensory-based intervention outcomes.

Understanding the lived experiences of children with challenges in sensory processing and integration may influence clinical reasoning and help pediatric occupational therapists collaborate with clients and their families more effectively regarding priorities for intervention. For example, Caroline strongly disliked writing. Mary believed she was capable of making progress if she would only try, which could have provided Caroline with an opportunity to overcome difficulties with finishing her work during the allotted class time. However, Caroline's family did not feel that she was capable of addressing her aversion to writing at that time. Frank (1996) stated that "Inequalities in power in clinical relationships...may suppress the voices of patients" (p. 259). Occupational therapists base their clinical reasoning on the best available evidence and, therefore, must listen to their client's perspectives in order to make the best recommendations for intervention. In the end the client's or family's wishes must be (and were) respected with regards to intervention priorities.

Understanding the lived experiences of children like Caroline who have challenges in sensory processing and integration is also important for expanding the research base of sensory integration interventions. Most of the existing research has utilized experimental or descriptive methodologies based on outcome measures, and the evidence is often contradictory. For example, standardized tests are intended to help clinicians and researchers formally recognize change (or lack thereof) due to intervention; however, they cannot necessarily capture change that occurs in areas outside the bounds of the test itself or discover the meaning change holds for the client

and his or her family. Qualitative research has the potential to provide perspectives on the value of “real world” outcomes regardless of their measurable goals. Caroline’s perspectives likely would not have been recognized by formal outcome measures.

Tomlin and Borgetto (2011) proposed that qualitative research should have an equitable standing amid experimental, outcomes, and descriptive research. Although the current levels of evidence hierarchy does not allow for the consideration of qualitative research in evidence-based practice, (Arbesman, Scheer, & Lieberman, 2008), incorporating the lived experiences of children with challenges in processing and integrating sensory information into the research base of sensory integration interventions may be merited through the rigor used to interpret the children’s perspectives and the natural fit between qualitative methodologies and the occupational therapy service delivery process (AOTA, 2008).

As suggested by Krefting (1991) and emphasized by Tomlin and Borgetto (2011), an audit trail, participant observation, triangulation of data, member checking, and peer review are a few of the steps to trustworthiness in qualitative research. These five steps were performed in this study. These five steps are also common components of occupational therapy service delivery found throughout evaluation, intervention, and outcomes. Creating an occupational profile typically involves some of the hallmarks of the qualitative phenomenological research method, such as subjective first-person responses to open-ended questions about the meaning behind life experiences (Denzin & Lincoln, 1998). These are three features employed by phenomenology to “convey information, to describe reality” (Holstein & Gubrium, 1998, p. 140). An occupational profile can also be considered a form of hermeneutical phenomenological qualitative

inquiry (Groenewald, 2004) as the occupational therapist endeavors to reserve judgment regarding the client's condition in order to understand a client's needs holistically (AOTA, 2008).

Limitations

This study had only one child participant. This makes the interpretations of the sole child's experiences less generalizable to a larger population. The researcher's previous knowledge of the participant could dilute the interpretation of her responses, although measures were taken to bracket biases (research journal). The amount of time elapsed since discharge could also impact the participant's responses, as she may not have accurately recalled her experiences before and during interventions that took place more than two years ago. For example, Caroline had little to say about familial interactions, could not remember what disciplinary problems she encountered in early grade school, and only related the "fun" aspects of therapy. Children with primary diagnosis of Tourette's syndrome, obsessive compulsive disorder, anxiety disorder, pervasive developmental disorder, autism, or fragile X were excluded from recruitment, assuming the non-sensory impairments that are part of these conditions would likely have limited participant insight as well as decreased transferability of the results. However, the treating therapist reported that many of her former clients with these conditions had demonstrated high capacity for insight and she believed they could have been appropriate candidates for the study. By excluding clients with these conditions, it is possible that some aspects of the lived experience of children receiving sensory-based occupational therapy intervention were missed.

Future research

It is important to continue qualitative research on the lived experiences of individuals with challenges in processing and integrating sensory information in order to understand the phenomena and expand the evidence base for sensory integration interventions. If the focus on lived experiences remains on children, recruiting children immediately upon discharge or during the final intervention sessions may yield more accurate or insightful responses. The possibility of developing a Likert-scale questionnaire to supplement the qualitative interview in data collection might also strengthen child responses.

Exploring the phenomena of challenges in processing and integrating sensory information and expanding the evidence base for sensory integration interventions should include the lived experiences of individuals of all ages when possible. Sensory integration interventions are becoming more popular outside of pediatric practice (Champagne, Koomar, & Olson, 2010; Watling et al., 2011). Adolescents and adults might have greater reflective abilities and insights regarding their conditions before and after intervention, and could be capable of providing richer descriptions and more in-depth responses that could justify the continued use of sensory integration interventions outside pediatric settings.

Conclusion

Only one child participated in this study, making the meaning and interpretation of her experiences less transferrable to the larger population of children with challenges in processing and integrating sensory information. However, coinciding responses from her parent and treating therapist showed that Caroline possessed accurate perceptions

of her challenges, the intervention process, and her outcomes. Caroline labeled and described maladaptive responses to sensory information that impacted her occupational participation and engagement at home, at school, and within her community. She also gave examples of adaptive strategies for addressing her residual challenges and recognized opportunities for their use in improving occupational participation and engagement. As well as coinciding with the perceptions of her parent and therapist, Caroline's descriptions and examples coincided with the perceptions of outcomes by parents of other children who had participated in sensory integration interventions. The responses Caroline provided suggest that children as young as 10 years old might be capable of providing meaningful insights about their life experiences with challenges in processing and integrating sensory information and outcomes resulting from sensory integration interventions. Caroline's responses also suggest that qualitative data on this topic can provide real world evidence for sensory integration and sensory-based interventions that is just as important as evidence obtained from experimental, descriptive, or outcomes studies used to establish evidence-based practices.

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Appendix A

Initial Recruitment Flyer

March 22nd, 2012

Dear Family:

My name is Andrea Johnson and I am an occupational therapy student at the University of Puget Sound in Tacoma. As partial fulfillment of my graduation requirements, I am conducting a research study entitled "Experiences With and Perceived Benefits from Occupational Therapy With a Sensory Integration-Based Approach as Reported by Children." My aim is to conduct interviews with children between the ages of eight and 12 regarding their experiences with occupational therapy and how their lives are different (or not) after receiving sensory integration-based intervention.

I have been observing and volunteering with [therapist] OTR/L, of [clinic] for the past two years. [therapist] has mailed your family this letter on my behalf because she feels that your child fits the criteria for my study.

Your family's participation in this study will be greatly appreciated, as it can provide insight into the therapeutic process. Your child's responses can expand the knowledge base of occupational therapy and help therapists guide children with challenges in sensory processing and integration toward their best possible outcomes.

If you agree to allow your child to participate in this study, interviews will be conducted in two parts. The first interview will last 30 to 45 minutes. The second interview will last 15 to 20 minutes. Only the first interview will be audio recorded, and the recording will be professionally transcribed.

Interviews must be conducted between 3/29/12 and 4/12/12. If you agree to allow your child to participate in this study, and one 30 to 45 minute interview and one 15 to 20 minute interview are possible between these dates, please:

- Read and sign the enclosed Parental Consent form
- Fill in the Demographic Questionnaire
- Return both documents in the envelope provided.

I will contact you via telephone at the number and preferred time of day you indicate. At that time, we will schedule an interview date, time, and location, as well as ways that I may structure the interview environment to support your child's sensory needs. Your child will also be asked to give informed consent to participate. If your child agrees to participate in this study, he/she will sign a form and the interview will begin. If your child declines to participate, you will be free to leave. No matter what your child decides to do, he/she will receive a \$15 gift card for the Barnes and Noble bookstore.

I will contact all families that respond to this letter, but I will only be able to schedule interviews with the first three. I will establish a backup list of families in the order that I am contacted and will notify them when their participation is needed or when the study has been completed.

Please contact me or my advisor with any questions or concerns at the telephone number or email address listed below.

Thank you,

Andrea Johnson, OTS
University of Puget Sound
253-879-3281
ajjohnsonerickson@pugetsound.edu

Renee Watling, PhD, OTR/L, FAOTA
University of Puget Sound
253-879-3281
rwatling@pugetsound.edu

Appendix B**Parental Consent Form****INFORMED CONSENT
TO ACT AS A SUBJECT IN
A RESEARCH STUDY**

PRINCIPAL INVESTIGATORS: Andrea L. Johnson, OTS, Renee Watling, PhD, OTR/L, FAOTA, Yvonne Swinth, PhD, OTR/L, FAOTA
Department of Occupational Therapy, 1500 N. Warner, CMB 1070, Tacoma, WA 98416;
253-879-3281; ajjohnsonerickson@pugetsound.edu, rwatling@pugetsound.edu,
yswinth@pugetsound.edu

STUDY TITLE: Experiences with and perceived benefits from occupational therapy with a sensory integration-based approach as reported by children

SUBJECT'S NAME:

Please read the following materials to make sure that you are informed of the nature of this study and of how you and your child will participate in it, if you agree to do so. Signing this form will indicate that you and your child understand what the study is about and that you have decided to participate.

PURPOSE/DESCRIPTION OF STUDY:

You and your child are being asked to take part in a research study. Researchers want to learn children's thoughts about how their lives have or have not changed after getting occupational therapy services. Your child has been asked to be in the study because he/she is between the ages of 8 and 12 years old and has received occupational therapy using a sensory integration-based approach. You and your child will be asked to take part in the study for two days. The first day is a 30 to 45 minute interview. The second day is a 15 to 20 minute follow-up interview.

Subject's Initials _____

PROCEDURES:

1. Your child will participate in a 30 to 45 minute interview. The interviewer will ask questions about therapy, school, friends, and home life. The interview will take place in a location selected by you and your child. You can be present during the interview.
2. We will study the interview for key words and phrases.
3. You and your child will participate in a 15 to 20 minute interview. The interviewer will ask you to evaluate the interpretation of the information gathered from the first interview. The interview will take place in a location selected by you and your child or over the phone. You and your child will both be present during the interview.

RISKS AND BENEFITS:

There is a risk that during the interviews your child may become sad, angry, or embarrassed. If at any point your child becomes distressed or does not like any of the questions he/she is being asked, your child is free to take a break, skip the question, or leave the interview.

The benefit of you and your child taking part in this study is in giving insight into the therapeutic process. This will help occupational therapists guide children with sensory dysfunction toward their best possible outcomes. For your child's participation in this study, he/she will receive a small thank you gift.

COST AND PAYMENTS:

There is no cost to participate in this study, and no monetary compensation will be given for participation. A small thank you gift will be given to your child for taking part in the study.

CONSENT TO BE AUDIOTAPED:

I give my consent for my child and myself to be audiotaped. I am aware that the recording will be utilized for data analysis and will be erased after five years. My child's actual name will not be used on the tape, transcription, or any other documents made from the tape.

CONFIDENTIALITY:

I understand that any information about me or my child obtained from this research, including answers to questions, history, audiotapes, or transcriptions will be kept strictly confidential. Information carrying personal identifying material will be kept in locked files. All written personal information will be destroyed after five years. I understand that my and my child's research records, just like hospital records, may be

Subject's Initials _____

subpoenaed by court order. It has been explained to me that my identity will not be revealed in any description or publication of this research. Therefore, I consent to such publication for scientific purposes.

RIGHT TO REFUSE OR TO END PARTICIPATION:

I understand that I am free to refuse my participation and my child's participation in this study or to end our participation at any time and that our decision will not adversely affect our care at this institution or within our school program, or cause a loss of benefits to which we might otherwise be entitled.

VOLUNTARY CONSENT:

I certify that I have read the preceding, or it has been read to me, and that I understand its contents. Any questions I have pertaining to the research have been or will be answered by Andrea Johnson, OTS, at the University of Puget Sound (253-879-3281). Any questions I have concerning my rights as a research subject will be answered by the Office of the Associate Deans (253-879-3207). A copy of this consent form will be given to me. My signature below means that I have freely agreed to participate and allow my child to participate in this experimental study.

SIGNATURES:

I have read or discussed this document with one of the investigators involved in the project and agree to participate and have my child participate.

Consent Signature of Parent or Person
Legally Responsible for Subject

Date

Signature of Witness

Date

INVESTIGATOR'S CERTIFICATION:

I certify that I have explained to the above individual the nature and purpose, the potential benefits, and possible risks associated with participating in this research study, have answered any questions that have been raised, and have witnessed the above signature.

Signature of Investigator or Member of Research Staff

Date

Appendix C

Demographic Questionnaire

Demographic Questionnaire

Child's first name:				
Age:	Date of birth:	Grade:	Gender: M F	Race:
Diagnosis/Reason for referral to occupational therapy:				
Residence: Urban Suburban Rural			Primary language spoken at home:	
Please describe your child regarding his/her personality, individual characteristics, sensory-based challenges and behaviors, habits, routines, etc.				
Please describe/list items in the environment that distract your child or cause him/her discomfort or distress:				
Please describe your child's typical signs of discomfort or distress (e.g.: behaviors that suggest a "meltdown" may occur):				

Please describe/list items in the environment that support your child's appropriate behavior or allow him/her to focus:

Please describe your child's preferences for handling discomfort/distress or preventing a "meltdown" (e.g. does he/she require a fidget or need to get up and move around?):

Please describe the process of how you came to be clients of [therapist].

When did child's occupational therapy begin?

What was the frequency of therapy?

When did therapy end?

Has child received or is child receiving school-based services?

Yes

No

When did services begin?

Which type(s)?

When did services end?

Has child received or is child receiving any other services?

Yes

No

When did service(s) begin?

Which type(s)?		When did service(s) end?		
Child's caregiver living at home: mother father biological adoptive other				
Caregiver age:	Caregiver education level:	Caregiver employment status:		
Child's caregiver living at home: mother father biological adoptive other				
Caregiver age:	Caregiver education level:	Caregiver employment status:		
Does child have siblings?		Yes	No	
Gender	Age	Birth order	Diagnosis?	Type
Do siblings receive therapy services?		Yes	No	
Sibling (birth order)	Service	When did services begin?	When did services end?	

Thank you for completing this questionnaire. Please provide a telephone number, time of day you would prefer to be contacted, and the first name of the caregiver to request in order to schedule the first interview.

Telephone number: _____

Time of day to be contacted: _____

Name of caregiver to contact: _____

Appendix D**Recruitment Reminder Letter**

April 24, 2012

Dear Family –

You recently received a recruitment packet for a research project entitled “Experiences With and Perceived Benefits from Occupational Therapy With a Sensory Integration-Based Approach as Reported by Children.” We are still recruiting participants.

Please consider participating in this important study that will help us to better understand how children perceive their experience with occupational therapy. We really want to know what kids have to say about this!

The study involves one 30 to 45 minute interview and one 15 to 20 minute interview. If you are interested and available to be interviewed prior to May 27th, please let me know as soon as possible. You can do this by:

- Reading and signing the enclosed Parental Consent form
- Completing the Demographic Questionnaire
- Returning both documents in the envelope provided.

I will contact you via telephone at the number you provide on the demographic questionnaire. We will schedule an interview date, time, and location, as well as discuss ways to structure the interview environment to support your child’s sensory needs.

Please contact me or my advisor with any questions or concerns at the telephone number or email addresses listed below.

Thank you for considering this exciting research opportunity,

Andrea Johnson, OTS
University of Puget Sound
253-879-3281
ajjohnsonerickson@pugetsound.edu

Renee Watling, PhD, OTR/L, FAOTA
University of Puget Sound
253-879-3281
rwatling@pugetsound.edu

Appendix E
Child Assent Form

**CHILDREN'S INFORMED ASSENT
FOR SUBJECTS AGES 8-12
TO ACT AS A SUBJECT IN
A RESEARCH STUDY**

PRINCIPAL INVESTIGATORS: Andrea L. Johnson, OTS, Renee Watling, PhD, OTR/L, FAOTA, Yvonne Swinth, PhD, OTR/L, FAOTA
Department of Occupational Therapy, 1500 N. Warner, CMB 1070, Tacoma, WA 98416;
253-879-3281; ajjohnsonerickson@pugetsound.edu, rwatling@pugetsound.edu,
yswinth@pugetsound.edu

STUDY TITLE: Experiences with and perceived benefits from occupational therapy with a sensory integration-based approach as reported by children

SUBJECT'S NAME:

* This form will be read to the child to ensure comprehension.

You have been invited to be in a research study, but before you say yes, we want to tell you about it so you can ask questions.

The people in charge of this study would like to know about your experience with occupational therapy.

The reason we are asking you to be in this study is because you are between the ages of 8 and 12 years old and you have received occupational therapy using a sensory integration-based approach.

Subject's Initials _____

The purpose of this study is to find out how you feel about your therapy sessions and if or how your life has changed. We want you to be completely honest. Your opinions can help occupational therapists do a better job at working with other kids just like you.

We will be asking you questions about therapy, and school, and friends, and home. If any questions make you uncomfortable, just tell us that you don't want to answer. You are free to take a break at any time. Or, if you decide that you don't want to be involved in this study at all, that's ok too. Stopping or not being in the study will not upset anyone. We will give you a small thank you gift no matter how much you participate.

Do you have any questions?

Do you want to tell us about your experiences with therapy?

My _____ (parent/guardian) knows about this and wants me to be in this study.

Child's Signature

Date

Parent/Guardian Signature

Date

Investigator Signature

Date

Witness Signature

Date

Appendix F

Parent as Subject Consent Form

**INFORMED CONSENT
TO ACT AS A SUBJECT IN
A RESEARCH STUDY**

PRINCIPAL INVESTIGATORS: Andrea L. Johnson, OTS, Renee Watling, PhD, OTR/L, FAOTA, Yvonne Swinth, PhD, OTR/L, FAOTA
Department of Occupational Therapy, 1500 N. Warner, CMB 1070, Tacoma, WA 98416;
253-879-3281; ajohnsonerickson@pugetsound.edu, rwatling@pugetsound.edu,
yswinth@pugetsound.edu

STUDY TITLE: Experiences with and perceived benefits from occupational therapy with a sensory integration-based approach as reported by children

SUBJECT'S NAME:

Please read the following materials to make sure that you are informed of the nature of this study and of how you, the caregiver of a child previously interviewed, will participate in it if you agree to do so. Signing this form will indicate that you understand what the study is about and that you have decided to participate.

PURPOSE/DESCRIPTION OF STUDY:

You are being asked to take part in a research study. Researchers want to learn children's thoughts about how their lives have or have not changed after getting occupational therapy services. Your child has already been interviewed, and you are being asked participate in the study in order to compare your perceptions of your child's therapy to those of your child. You are being asked to take part in the study for two days. The first day is a 30 to 45 minute interview. The second day is a 15 to 20 minute follow-up interview.

Subject's Initials_____

PROCEDURES:

1. You will participate in a 30 to 45 minute interview, which will be audio recorded. The interviewer will ask questions about your child’s therapy, school, friends, and home life. The interview will take place in a location selected by you.
2. We will transcribe the audio recordings and study the transcribed interview for key words and phrases in order to summarize your perceptions of your child’s experience with occupational therapy.
3. You will participate in a 15 to 20 minute interview, which will not be audio recorded or transcribed. The interviewer will ask you to evaluate the summary of the information gathered from the first interview. The interview will take place in a location selected by you or over the phone.

RISKS AND BENEFITS:

There is a risk that during the interviews you may become sad, angry, or embarrassed. If at any point you become distressed or do not like any of the questions being asked, you are free to take a break, skip the question, or leave the interview.

The benefit of your participation in this study is in giving insight into the therapeutic process. This will help occupational therapists guide children with sensory dysfunction toward their best possible outcomes. For your participation in this study, you will receive a \$15 gift card for Starbucks.

COST AND PAYMENTS:

There is no cost to participate in this study, and no monetary compensation will be given for participation. A small thank you gift will be given for taking part in the study.

CONSENT TO BE AUDIOTAPED:

I give my consent to be audio recorded for data analysis. Because identifying information will be given during the interview, the recording will be destroyed after its professional transcription.

CONFIDENTIALITY:

I understand that any information about me obtained from this research will be kept strictly confidential. Contact information and consent forms requiring identifying information will be kept in a locked file in room 107 of the Weyerhaeuser building at the University of Puget Sound. Digital data will be kept on a password-secured laptop. Audio recordings will be destroyed after being professionally transcribed. Identifying information will be eliminated from transcriptions. My name will be replaced with a pseudonym.

Subject’s Initials _____

Names of other identifiable items will be replaced with a generic term, such as "clinic" or "school" or "therapist." All data will be destroyed five years from final submission of thesis in June, 2012. I understand that my research records, just like hospital records, may be subpoenaed by court order. It has been explained to me that my identity will not be revealed in any description or publication of this research. Therefore, I consent to such publication for scientific purposes.

RIGHT TO REFUSE OR TO END PARTICIPATION:

I understand that I am free to refuse my participation in this study or to end my participation at any time and that my decision will not adversely affect care at this institution or within the school program, or cause a loss of benefits to which I might otherwise be entitled.

VOLUNTARY CONSENT:

I certify that I have read the preceding, or it has been read to me, and that I understand its contents. Any questions I have pertaining to the research have been or will be answered by Andrea Johnson, OTS, at the University of Puget Sound (253-879-3281). Any questions I have concerning my rights as a research subject will be answered by the Office of the Associate Deans (253-879-3207). A copy of this consent form will be given to me. My signature below means that I have freely agreed to participate in this experimental study.

SIGNATURES:

I have read or discussed this document with one of the investigators involved in the project and agree to participate.

Consent Signature of Parent or Person Legally Responsible for Subject Date

Signature of Witness Date

INVESTIGATOR'S CERTIFICATION:

I certify that I have explained to the above individual the nature and purpose, the potential benefits, and possible risks associated with participating in this research study, have answered any questions that have been raised, and have witnessed the above signature.

Signature of Investigator or Member of Research Staff Date

Appendix G

Therapist Consent Form

**INFORMED CONSENT
TO ACT AS A SUBJECT IN
A RESEARCH STUDY**

PRINCIPAL INVESTIGATORS: Andrea L. Johnson, OTS, Renee Watling, PhD, OTR/L, FAOTA, Yvonne Swinth, PhD, OTR/L, FAOTA
Department of Occupational Therapy, 1500 N. Warner, CMB 1070, Tacoma, WA 98416;
253-879-3281; ajjohnsonerickson@pugetsound.edu, rwatling@pugetsound.edu,
yswinth@pugetsound.edu

STUDY TITLE: Experiences with and perceived benefits from occupational therapy with a sensory integration-based approach as reported by children

SUBJECT'S NAME:

Please read the following materials to make sure that you are informed of the nature of this study and of how you, the treating occupational therapist of a child previously interviewed, will participate in it if you agree to do so. Signing this form will indicate that you understand what the study is about and that you have decided to participate.

PURPOSE/DESCRIPTION OF STUDY:

You are being asked to take part in a research study. Researchers want to learn children's thoughts about how their lives have or have not changed after getting occupational therapy services. A child you have previously treated and discharged from therapy has already been interviewed, and you are being asked participate in the study in order to compare your perceptions of the child's therapy to those of the child. You are being asked to take part in the study for two days. The first day is a 30 to 45 minute interview. The second day is a 15 to 20 minute follow-up interview.

Subject's Initials _____

PROCEDURES:

1. You will participate in a 30 to 45 minute interview, which will be audio recorded. The interviewer will ask questions about the child's status at intake, therapy sessions, and the child's status at discharge. The interview will take place in a location selected by you.
2. We will transcribe the audio recordings and study the transcribed interview for key words and phrases in order to summarize your perceptions of the child's experience with occupational therapy.
3. You will participate in a 15 to 20 minute interview, which will not be audio recorded or transcribed. The interviewer will ask you to evaluate the summary of the information gathered from the first interview. The interview will take place in a location selected by you or over the phone.

RISKS AND BENEFITS:

There is a risk that during the interviews you may become sad, angry, or embarrassed. If at any point you become distressed or do not like any of the questions being asked, you are free to take a break, skip the question, or leave the interview.

The benefit of your participation in this study is in giving insight into the therapeutic process. This will help occupational therapists guide children with sensory dysfunction toward their best possible outcomes. For your participation in this study, you will receive a \$15 gift card for Starbucks.

COST AND PAYMENTS:

There is no cost to participate in this study, and no monetary compensation will be given for participation. A small thank you gift will be given for taking part in the study.

CONSENT TO BE AUDIOTAPED:

I give my consent to be audio recorded for data analysis. Because identifying information will be given during the interview, the recording will be destroyed after its professional transcription.

CONFIDENTIALITY:

I understand that any information about me obtained from this research will be kept strictly confidential. Contact information and consent forms requiring identifying information will be kept in a locked file in room 107 of the Weyerhaeuser building at the University of Puget Sound. Digital data will be kept on a password-secured laptop. Audio recordings will be destroyed after being professionally transcribed. Identifying information will be eliminated from transcriptions. My name will be replaced with a pseudonym.

Subject's Initials _____

Names of other identifiable items will be replaced with a generic term, such as “clinic” or “school.” All data will be destroyed five years from final submission of thesis in June, 2012. I understand that my research records, just like hospital records, may be subpoenaed by court order. It has been explained to me that my identity will not be revealed in any description or publication of this research. Therefore, I consent to such publication for scientific purposes.

RIGHT TO REFUSE OR TO END PARTICIPATION:

I understand that I am free to refuse my participation in this study or to end my participation at any time and that my decision will not adversely affect care at this institution or within the school program, or cause a loss of benefits to which I might otherwise be entitled.

VOLUNTARY CONSENT:

I certify that I have read the preceding, or it has been read to me, and that I understand its contents. Any questions I have pertaining to the research have been or will be answered by Andrea Johnson, OTS, at the University of Puget Sound (253-879-3281). Any questions I have concerning my rights as a research subject will be answered by the Office of the Associate Deans (253-879-3207). A copy of this consent form will be given to me. My signature below means that I have freely agreed to participate in this experimental study.

SIGNATURES:

I have read or discussed this document with one of the investigators involved in the project and agree to participate and have my child participate.

Consent Signature of Parent or Person Legally Responsible for Subject	Date
--	------

Signature of Witness	Date
----------------------	------

INVESTIGATOR’S CERTIFICATION:

I certify that I have explained to the above individual the nature and purpose, the potential benefits, and possible risks associated with participating in this research study, have answered any questions that have been raised, and have witnessed the above signature.

Signature of Investigator or Member of Research Staff	Date
---	------

Appendix H

Child Interview Guide

1. Let's talk about life before coming to see [therapist] (occupational therapy).
 - a. What was it like at home?
 - i. Tell me about a typical day at home.
 - ii. How were things between you and your parents?
 - iii. How were things between you and your brothers/sisters?
 - iv. Did you get dressed by yourself? What about bathing, brushing your teeth, combing your hair, things like that?
 - v. Did you have any chores?
 - b. Tell me about school.
 - i. Tell me about a typical day at school.
 - ii. How did you do in class?
 - iii. Was anything hard for you (reading, math, PE, recess)?
 - iv. How was your behavior?
 1. Did you get into trouble at all?
 - c. Participation in activities?
 - i. How many?
 - ii. What types?
 - iii. Did you enjoy it/them?
 - iv. Are you successful?
 - d. Tell me about your friends.
 - i. Who did you like to hang out with the most?
 - ii. Why?
 - iii. What did you do together?
 - iv. Were they really close or just casual?
 - v. Tell me about a typical play experience with a friend or classmates.
 - vi. Did you ever play at their homes or stay overnight?
 1. How did that go?
 - vii. Did you have friends over or have them stay overnight?
 1. How did that go?
2. Please tell me about the time you spent with [therapist] (occupational therapy).
 - a. Why did you go to see [therapist]?
 - b. Was there anything you were hoping [therapist] would help you with?
 - c. What kinds of activities did you do?
 - d. What were your favorite activities?
 - e. How do you feel about being done with therapy?
3. Have you had any other types of therapy?

- a. What were they?
 - b. Why did you go there?
 - c. Was there anything you were hoping the therapist(s) could help you with?
 - d. What kinds of activities did you do?
 - e. What were your favorite activities?
 - f. How do you feel about being done with therapy(ies)?
 - g. Do you think the other therapy(ies) helped you work better when you went to see [therapist]?
4. Please tell me about life after working with [therapist].
- a. What is it like at home now?
 - i. Tell me about a typical day at home now.
 - ii. How are things between you and your parents?
 - iii. How are things between you and your brothers/sisters?
 - iv. Do you get dressed by yourself? What about bathing, brushing your teeth, combing your hair, things like that?
 - v. Do you have any chores?
 - b. Tell me about school.
 - i. Tell me about a typical day at school now.
 - ii. How are you doing in class?
 - iii. Is anything still hard for you (reading, math, PE, recess)?
 - iv. How is your behavior?
 - 1. Do you get into trouble at all?
 - c. Participation in activities now?
 - i. How many?
 - ii. What types?
 - iii. Do you enjoy them?
 - iv. Are you successful?
 - d. Tell me about your friends.
 - i. Who do you like to hang out with the most now?
 - ii. Why?
 - iii. What do you do together?
 - iv. Are they really close or just casual?
 - v. Tell me about a typical play experience with a friend or classmates now.
 - vi. Do you ever play at their homes or stay overnight?
 - 1. How does that go?
 - vii. Do you have friends over or have them stay overnight?
 - 1. How does that go?

Appendix I

Parent Interview Guide

1. Tell me about life with [child] before occupational therapy.
 - a. Describe a typical day at home.
 - i. How did you get along with [child]?
 - ii. How did [child] get along with siblings?
 - iii. Describe [child's] self-care performance.
 - b. Describe a typical day at school for [child].
 - i. How did [child] do in class?
 - ii. Was anything difficult for [child]?
 - iii. How was [child's] behavior?
 - c. Participation in activities?
 - i. How many?
 - ii. What types?
 - iii. Did [child] enjoy it/them?
 - iv. Was [child] successful?
 - d. Tell me about [child's] friends.
 - i. Were they really close or just casual?
 - ii. Tell me about a typical play experience with a friend or classmates.
 - iii. Did [child] ever play at their homes or stay overnight?
 1. How did that go?
 - iv. Did [child] have friends over or have them stay overnight?
 1. How did that go?
2. Tell me about [child's] experiences with/during occupational therapy.
 - a. Why did [child] go to see [therapist]?
 - b. Was there anything you were hoping she would help [child] with?
 - c. What kinds of activities did [child] do?
 - d. What were [child's] favorite activities?
 - e. How do you feel about [child] being done with therapy?
3. Tell me about the other types of therapy [child] has had.
 - a. What were they?
 - b. Why did you go there?
 - c. Was there anything you were hoping the therapist(s) could help [child] with?
 - d. What kinds of activities did [child] do?
 - e. What were [child's] favorite activities?
 - f. How do you feel about [child] being done with therapy(ies)?
 - g. Do you think the other therapy(ies) helped [child] work better with [therapist]?
4. Tell me about life with [child] after occupational therapy.

- a. Describe a typical day at home now.
 - i. How do you get along with [child]?
 - ii. How does [child] get along with siblings?
 - iii. Describe [child's] self-care performance.
- b. Describe a typical day at school for [child].
 - i. How does [child] do in class?
 - ii. Is anything difficult for [child]?
 - iii. How is [child's] behavior?
- c. Participation in activities now?
 - i. How many?
 - ii. What types?
 - iii. Does [child] enjoy it/them?
 - iv. Is [child] successful?
- d. Tell me about [child's] friends.
 - i. Are they really close or just casual?
 - ii. Tell me about a typical play experience with a friend or classmates now.
 - iii. Does [child] ever play at their homes or stay overnight?
 1. How does that go?
 - iv. Does [child] have friends over or have them stay overnight?
 1. How does that go?

Appendix J**Therapist Interview Guide**

1. Describe the status of [child] when she first came to therapy.
 - a. What was [child] referred for?
 - b. What was [child's] behavior during testing?
 - c. What tests/observations were conducted with [child]?
 - d. What was your hypothesis about [child's] needs?
 - e. Describe [child's] treatment plan.
2. Tell me about [child's] experiences with/during therapy.
 - a. What kinds of activities did [child] do?
 - b. What were [child's] favorite activities?
 - c. Summarize [child's] performance of activities over time.
3. Describe the status of [child] at discharge.
 - a. What were you hoping/thinking [child] would make the most gains with?
 - b. How do you feel about [child] being done with therapy?
 - c. How do you think [child] feels about being done with therapy?
 - d. If [child] returns to therapy, what do you think will be [child's] needs?

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