

## Children's Sensory Experiences and Family Occupations

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Abstract  
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This qualitative study employed a grounded theory approach to data analysis to discover what effect, if any, children's sensory experiences have on family occupations. A grounded theory approach was chosen because existing occupational therapy and occupational science literature does not provide a theory to account for the effect of children's sensory experiences on family occupations. Parents of 12 children were interviewed. Six of the children were typically developing and six children had autism. The interviews were transcribed verbatim and analyzed using open, axial, and selective coding techniques. I found that children's sensory experiences affect family occupations in three ways. Children's sensory experiences affect: (a) what a family chooses to do or not do; (b) how the family prepares; and (c) the extent to which experiences, meaning, and feelings are shared.

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## Chapter 1: Introduction

The intent of this qualitative study is to understand what effect children's sensory experiences have on family occupations. This study examined families who have children with autism and families who have typically developing children. My goal was to understand how family routines incorporate children's sensory experiences at home and in the community. Two challenges exist with current occupational therapy literature on the subject of sensory processing in children with autism: (a) little attention has been given to how sensory experiences impact family occupations; (b) typically developing children are often used as a control group in quantitative studies alongside children with autism in order to contrast between the groups, rather than to identify overlaps. It is possible that the impact of sensory experiences on occupations of children with autism and those who are typically developing may fall on a continuum not captured by existing measures. Few qualitative studies exist that examine the sensory experiences of both children with autism and children who are typically developing. One exception is the qualitative work of Dickie, Baranek, Schultz, Watson, and McComish (2009), which examines children's sensory experiences, generates parents' perceptions and explanations of these experiences, and describes these experiences for children with and without autism.

A more balanced picture of similarities and differences in the occupations of families with typically developing children and children with autism can be created by discovering what effect, if any, children's sensory experiences have on family occupations. Segal (1999) stated, "Studies of family occupations among families with ordinary children and studies of the experiences of children during family occupations are needed" (p. 7). I have two hopes for this study: (a) that occupational therapists will gain a better understanding of the sensory aspects of family occupations, thereby

enabling us to provide more family-centered treatment embedded in naturally occurring family occupations; (b) that the parent of any child, with or without autism, will appreciate the richness and importance of sensory experiences in everyday routines and occupations.

For the purposes of this paper, a sensory experience is defined as: (a) an event where an individual is affected by a stimulus to one or more of the senses, (b) processes the input to the sensory system(s), and (c) responds in some way. The response is an observable behavior (e.g., giggling or throwing a temper tantrum), and can be emotional (e.g., appearing joyful or hurt) or physical (e.g., jumping around or putting fingers in one's ears). As defined in the Occupational Therapy Practice Framework (OTPF), the client factors of 'sensory functions' include seeing and related functions, hearing functions, vestibular functions, temperature and pressure, as well as taste smell, touch, and proprioceptive functions (American Occupational Therapy Association, 2008). Two examples of sensory experiences are swinging at a playground and eating a crunchy peanut butter sandwich. These sensory experiences include input to sensory functions (e.g., vestibular functions, proprioception, taste, and/or touch). These examples of sensory experiences also include contextual elements that could provide additional sensory input. Swinging at a playground in a park might include contextual sensory input such as sun, wind, and chirping birds. The context for eating a peanut butter sandwich could be a quiet kitchen or a noisy shopping center, each providing distinctive sensory stimuli.

The notion that family occupations could be affected by sensory experiences is supported by existing occupational therapy theories. Dunn, Brown, and McGuigan (1994) proposed the Ecology of Human Performance (EHP) framework in which it is impossible to see a person without seeing his/her context. EHP relates to this study because any given context includes potential sensory experiences. Dunn, et al. stated, "Persons use their skills and abilities to look through the context at the tasks they need or want to do. They derive meaning from this process" (p. 600). Dunn, et al. also proposed that each person has a performance range that enables one to perform tasks using one's skills, abilities, and context. EHP provided us with an understanding of how a person, within a context that includes sensory elements, can engage in occupations. Yet the concept of family



occupations requires that we go a step further in our explanation to determine how an individual's performance range can then impact others' routines and occupations.

Alternatively, Law et al.'s Person-Environment-Occupation (PEO) model (1996) showed how the person, the environment, and occupation constantly interact and give rise to occupational performance. Experiences are gained across the course of life through the interaction that occurs among the person, environment, and occupation (Law, et al.). Law, et al.'s model contends that our experiences throughout life build on one another and affect all future interactions. This model is also useful in explaining how family occupations could be affected by children's sensory experiences. Each family member brings individual experiences, including sensory experiences, into every family occupation. In the same way, family occupations can create new sensory experiences. Experience, in turn, affects 'fit' between the person, environment, and occupation. Law et al.'s PEO model could help to describe how children's sensory experiences affect 'fit' of family occupations.

Humphry and Case-Smith (2005) discussed the concept of a family systems model. This model helped us to understand a family as a dynamic system, made up of interdependent individuals with "reciprocal influences on each other's occupations" (p. 119). The family itself is viewed as an open system, influenced by its environment (Humphry & Case-Smith). For example, the sensory aspects of a family occupation such as dinner in a restaurant can impact the routines and occupations of each member of the family system. Reciprocally, the actions of any member of the family during dinner can also influence other family members.

This study builds on existing literature to provide a grounded theory to help explain how children's sensory experiences affect family occupations. Existing literature describes families as dynamic systems (Humphry & Case-Smith, 2005) and explains how experience (Law, et al., 1996) and contextual elements in the environment (Dunn, et al., 1994) can affect a person's occupations. This study helps to clarify how sensory experiences affect the dynamic systems within a family. It also helps to explain how a family's performance range (i.e., the occupations the family chooses to do

or feels able to do) can be affected by sensory elements of the environment. Lastly, this study addresses how children's sensory experiences can affect the 'fit' of particular family occupations.

## Chapter 2: Literature Review

The main topics of literature reviewed were: (a) family occupations, routines, and rituals; (b) characteristics of and sensory experiences in people with autism; and (c) occupations in families of children with autism. I focused on these three areas because the topics informed my perspective on existing theories and knowledge related to sensory experiences in people with autism, as well as family occupations and routines, especially those in families of typically developing children and children with autism. These three topics also stimulated questions throughout this study and helped to situate the findings (Strauss & Corbin, 1990). However, the intent of the grounded theory approach is to develop a new theory and not feel, as Strauss and Corbin described, “constrained” or “stifled” (p. 50) by existing literature; thus the literature review was not exhaustive of all sources on any one topic.

### *Family Occupations*

Humphry and Case-Smith (2005) stated that, “Family occupations occur when daily activities and special events are shared by family members” (p. 118). Segal (1999) defined family occupations as “culturally meaningful chunks of activities” that “occur when the whole family is engaged in an occupation together” (p. 1). Family occupations can occur in a number of areas of occupation, including, but not limited to, activities of daily living, leisure, and instrumental activities of daily living. Examples of family occupations include a family eating dinner together, a mother bathing her toddler, or a father and his three children playing tennis. Segal stated the three purposes of family

occupations with children with special needs are: “being together; sharing; and affording learning opportunities” (p. 1). Humphry and Case-Smith proposed four outcomes of family occupations:

(a) establishing a cultural foundation for learning occupations that enables children to participate in a variety of contexts; (b) helping shape children’s basic sense of identity and emotional well-being; (c) helping children learn to master routines and habits that support physical health and well-being; and (d) fostering readiness to learn and to participate in educational programs. (p. 119)

These suggested purposes and outcomes help one to understand why family occupations are so critical to the development of a child and his/her occupations, but they do not address development of the family. Since the family is viewed as an open system (Humphry & Case-Smith), it is important to focus on how family occupations contribute to the development of the whole family rather than on child development alone.

Some researchers in disciplines outside of occupational science, such as Tubbs, Roy and Burton (2005), referred to family time rather than family occupations. The definition of family time closely resembles that of family occupations. In their study of family time in low income families, Tubbs, et al. referred to family time as time spent together to foster the family relationship and to create positive or memorable outcomes. In low income families, family time is often constructed and embedded in everyday family activities. Tubbs, et al. suggested that family time “affirms family commitments, family well-being, and positive affect” (p. 80). Four categories of activities that provide the contexts for parent-child interaction were also identified by Tubbs, et al. The four categories are: “talk time, mealtime, playtime, and sharing treats” (Tubbs, et al., p. 82). Sharing treats included sharing sweets or fast food or allowing the children to accompany the parent on an outing. The authors highlighted that for many families, family time involves spending money (e.g., going out to dinner, going to an amusement park, or going on vacation). Yet the study also emphasized the importance of promoting family time, even if the family has minimal financial resources, by embedding family time in everyday activities (e.g., while running errands or while in the car). My approach for this study was more closely aligned with the views of Segal (1999) and Tubbs, et al.,

who focus on the development of the family, in contrast to Humphry and Case-Smith's proposed outcomes of family occupations (2005) that are oriented to the development of the child.

Fiese (2006), a psychologist, also talked about the notion of family time rather than using the term family occupations. She suggested that family time is not objective and universal, but is rather a cultural construction that "reflects family beliefs about what is important in maintaining a cohesive group" (p. 39). In discussing family time, Fiese stated that it is important to keep the meaning of the routine and the feelings of family connectedness to the routines in mind. Some family rituals or routines performed daily (e.g., family dinner time) may or may not be as meaningful as time spent in other family rituals or routines performed only a few times per year (e.g., birthday celebrations).

In a qualitative study of mothers of young children with disabilities, Kellegrew (2000) proposed that the daily occupations of the families she studied were shaped by "the simultaneous process of accommodating to ecocultural influences and anticipating future possibilities" (p. 252). The children she studied were afforded various levels of participation in occupations, such as brushing their teeth, dressing, and eating, based on the mothers' perceived importance of the goal for their children in the future. For example, Kellegrew found that mothers interested in placing their children in a regular preschool were more interested in appropriate social skills and independence in self-care. Kellegrew also found that, "the time demands of self-care routines were a pivotal factor in the types and consistency of children's self-care occupations" (p. 258). For example, if a child takes too long to feed himself or herself breakfast, the child might not be afforded the opportunity to participate in the occupation.

*Family routines.* Family routines, according to Humphry and Case-Smith, "include interactive rituals that take on symbolic meaning and seem so matter of course that people do not think of doing them any other way and resist changing them" (2005, p. 120). Crowe (2002) proposed various types of routines that might exist in a family. For example, Crowe asserted that daily routines can be child-focused routines (e.g., two children playing together at a play date every Thursday

morning), couple-focused routines (e.g., a weekly parent bowling league), mealtime routines (e.g., sitting in the same seats for every meal), parent-child routines (e.g., a bedtime routine), family-togetherness routines (e.g., attending church together every Sunday), routines with other relatives (e.g., going to grandmother's house for dinner on Sunday), and/or family management routines (e.g., a father and son doing regular chores).

A number of authors have written about mealtime, including Fiese (2006, 2007), Evans and Rodger (2008), Kellegrew (2000), Segal (1999, 2004), and Tubbs, et al. (2005). Fiese (2006) pointed out important routine elements of mealtime, such as seat assignments, manners, role assignment, conversational turn-taking, and attendance, which convey cultural content. She also emphasized that participation in mealtimes signifies belonging to a group. Dinner time has been described as a time for building the family (DeVault as cited in Segal, 2004), during which children become acquainted with family values, such as gender roles and conflict resolution (Ochs, Taylor, Rudolph & Smith as cited in Segal, 2004). Segal (1999) highlighted the importance of sharing during the family occupation of mealtime as she explained that food and eating are less important compared to the interaction and behaviors expected. Fiese (2007) found that quality communication (e.g., direct communication and interest in others) during mealtimes is associated with improved health outcomes, whereas "poor eating habits become associated with poorly regulated family routines that include a dysregulated emotional and communication climate" (p. 46S). Mealtime is, therefore, an important family occupation, which includes habit and routine elements that convey culture and meaning to the participants.

Fiese (2006) and Segal (2004) separated routine from ritual. Fiese stated, "Routines and rituals can be contrasted along the dimensions of communication, commitment, and continuity" (p. 10). She went on to propose that routines are "instrumental...perfunctory and momentary...[and] directly observable and detectable by outsiders" (p. 11). By contrast, she said that rituals are "symbolic...enduring and affective... [and] meaning extends across generations and is interpreted by insiders" (p. 11). Segal said that family celebrations and traditions are rituals that convey family

identity, whereas routines are patterned behaviors that have instrumental goals, such as setting the table before meals or brushing teeth twice a day. Segal stated, “Routines give life order whereas rituals give it meaning” (p. 499).

While I understand Fiese and Segal’s points, from an occupational therapy perspective, I think that separating routine from ritual is nearly impossible. Just as I believe that a person is inextricably linked to his/her context, I do not think that we can separate an action from the meaning behind it. The examples of routines proposed by Segal (2004), such as setting a table and brushing your teeth, have some meaning to the person performing the action. When setting a table, the dishes and silverware chosen, as well as the way in which a place setting is arranged, convey meaning. If a person setting a table puts a fork on one side of the plate and a knife and spoon on the other side, the individual is demonstrating that he/she has learned this method of arranging the utensils through some sort of learning experience (i.e., cultural construct), thus conveying meaning. Therefore, I feel that it is impossible to remove meaning from any activity.

Additionally, it should be noted that some people, especially people with autism, may engage in a ritual because of cultural expectations (e.g., going to an aunt’s house for Christmas dinner) or personal compulsions (e.g., turning lights on and off twice before leaving a room) rather than because the act retains especially meaningful personal significance. Therefore, the separation of routine and ritual is problematic because significant meaning may be attached to some routines, while particular rituals may be performed to meet other people’s expectations rather than because of personal meaning related to the ritual. It is interesting to note that the impetus for separating routine and ritual stems from the work of Fiese, a psychologist. Perhaps occupational scientists and occupational therapy practitioners could be better served by revisiting these concepts from our discipline’s perspective.

Evans and Rodger (2008) also addressed the topic of family routines and rituals in a qualitative study conducted with typically developing preschool children. These authors viewed routines and rituals to be on a continuum (Evans & Rodger). The study focused on mealtime and bedtime routines and rituals. Although I disagree with the authors’ separation of routines from rituals

for aforementioned reasons, this study made an important point: routines are powerful. Evans and Rodger described the significance of the children's participation in family routines and rituals in terms of the family time shared together and the sense of identity fostered during the family routines. The authors highlighted the significance of quality time and the feelings of togetherness experienced during mealtimes and bedtimes. Evans and Rodger also emphasized the planning and prioritizing inherent in maintaining a family routine or ritual.

Families settle into routines based on a cultural model (Humphry & Case-Smith, 2005). Gallimore and Lopez (2002) defined a cultural model as, "the mental schema into which people code their interpretations of the environment and events, what is valued and ideal, which activities should be enacted and which avoided, who should participate, how people should interact, and so forth" (p. 72S). Gallimore and Lopez also proposed that cultural models are so "familiar and mundane" (p. 72S) that they often go unnoticed until people leave their own cultural model to and try to take on models of others. This further illustrates my point with regard to the examples of routines provided by Segal (2004). Setting a table and brushing one's teeth appear so mundane that we take the meaning behind these tasks for granted until we are faced with a routine constructed by an unfamiliar culture. Culture, therefore, defines an ideal routine (Gallimore & Lopez).

Gallimore, et al. (as cited in Kellgrew, 2000) proposed an ecocultural theory, in which families are driven by constructing and sustaining daily routines. For example, in Kellgrew's study of mothers with young children with disabilities, she found that, "The daily routines that mothers created were those that met two criteria: (a) must be within the child's potential ability and (b) was required to meet a future demand" (p. 258). Kellegrew stated that all family activities, including daily routines, reveal cultural values that influence how a family lives and what they choose to do. She further proposed that cultural practices are embedded in routines, such as mealtime and dressing, which reflect the family's predominant cultural orientation (e.g., Western orientation). Tubbs, et al. (2005) demonstrated how cultural factors can shape family time, and therefore family routines, in their study of low income families. They found that changing temporal routines (e.g., a parent who works



different shifts throughout the week), the importance of television time, and the emotional burdens related to poverty influence family time.

Harkness, et al. (2007) put forth the construct of a “developmental niche,” which is also culturally constructed. Although this construct emphasized the development of the child rather than the development of the family, it is another example of the influence of culture on daily routines. Harkness, et al. stated that the developmental niche framework is useful for “deriving a generalized description of recurring patterns characteristic of particular cultural communities” (p. 34S). The authors went on to discuss three components of the developmental niche, especially influential in the development of children with special needs, which are: “settings of daily life, customs of care, and the psychology of the caretakers” (p. 33S). These three components led Harkness, et al. to propose that parents’ developmental agendas for their children are culturally constructed, which may lead to certain areas of development taking precedence over other areas. Harkness, et al. stated, “This observation may be especially useful for fields such as occupational therapy because it offers therapists and parents the opportunity to ‘discover’ otherwise neglected dimensions of development that may turn out to be important to their child’s successful participation” (p. 38S). They also proposed that conversations with parents can be used to access the psychology of the caretaker.

Gallimore and Lopez (2002) proposed that routines allow families freedom to shape their daily life, yet that routines are also a compromise between what is desirable and what is practical. Additionally, Gallimore and Lopez stated, “Habitual daily routines that give shape and texture to individual, family, and professional life are governed not just by humans’ internal mechanisms (e.g., their cultural models and human agency) but by the environment in which they live” (p. 75S). Internal and external forces can press a family to change or adapt (Humphry & Case-Smith, 2005). A dynamic family systems perspective was reinforced by Fiese (2006) when she said that families change as a part of the natural transactional process. Mothers, for example, can be the family members responsible for establishing or changing family routines. In a qualitative study of mothers with preschool-age children, Francis-Connolly (2002) provided an example how changes and

unpredictability within a family system can alter family routines. She found that young children create unpredictability in family habits. She also found that mothers struggle to establish new, adaptive habits, which adds to the intensity of motherhood. Additionally, Francis-Connolly proposed that the unpredictability of daily life requires that the tasks of motherhood, including care-taking, nurturing, and teaching, become “enfolded” (p. 94) in daily routines.

According to Fiese (2007), there are supportive and disruptive elements of routines. When routines encompass planning, structure, and effective management strategies they provide a sense of belonging; whereas when routines are extremely rigid, or conversely, extremely chaotic, a sense of resentment can develop. She said that multiple members of a family must cooperate and be involved to maintain individual health in a chaotic world. Fiese stated:

The household production of health includes activities associated with supporting healthy child development, preventing disease, coping with illness and recovery, and communicating with healthcare professionals. These activities are part of the family’s daily routines that include eating and sleeping habits, shopping for and preparing food, arranging transportation, and keeping a schedule. (p. 42S)

It then becomes apparent that a family’s daily routine can influence the health of the household.

In families with children with disabilities, the family routines and the values linked to the routines change over time (Crowe, 2002). Kellegrew’s qualitative study (2000) found that cultural expectations and parents’ future visions for their children influenced daily occupations within families. Bernheimer and Weisner (2007), who also took an ecocultural perspective, proposed that accommodation is typically the way that families with children with disabilities adapt routines. The authors defined accommodations as, “the intentional adjustments made by families to sustain a daily routine” (p. 193). These accommodations can include actions taken or not taken, in order to sustain daily routines. In their qualitative study of 105 families over 15 years, Bernheimer and Weisner identified five key findings related to accommodations in families with children with disabilities:

- (a) accommodations are usually adaptations to everyday routines, not responses to stress;
- (b) accommodations are responsive to how children impact parents' daily routine, not to children's test scores;
- (c) accommodations are related to parents' differing goals and values;
- (d) accommodations do not fit a single script or model for what is good or bad parenting; and

(e) accommodations predict family sustainability of daily routines, rather than child outcomes. (p. 192)

Humphry and Case-Smith (2005) stated that communication among family members, as well as the reconstruction or creation of daily routines, are critical components of family resiliency when a family is faced with the need to adapt.

Routines appear to have many benefits in families of children with disabilities (Fiese, 2006). Fiese proposed that establishment of routines in family life may contribute to feelings of parental competence and efficacy. Family commitment to routines and rituals has also been associated with higher achievement test scores, academic achievement, self-regulation, and behavioral adjustment. Additionally, regular family-based routines have been associated with better health for individuals with various chronic conditions. This association likely occurs for a few reasons. First, predictability and order in a household have been associated with better overall physical health. For example, when medications are administered to a child as part of a regular routine, adherence rates improve. Second, routines promote involvement of multiple family members and monitoring of one another's behaviors. Third, emotional components of routines may play a role in improving family health (Fiese).

The emotional components of routines cannot be underestimated. As discussed in the aforementioned ecocultural perspective, values and culture are transmitted through routines and rituals (Fiese, 2006). Fiese stated, "The meaning and affect associated with rituals provide relief and at the same time help create a family identity that is multifaceted rather than tied to a single condition" (p. 90). She suggested that a family as a whole is greater than the sum of the individual parts. Implementation of regular routines may reduce caregiver burden and improve mental health and emotional well-being of the caregiver. Through the transactional nature of family systems, improved psychological well-being of caregivers can improve the well-being of other members of the family, including children (Fiese). Segal (2004) supported the emotional and transactional nature of

routines, proposing that the enactment of roles conveys as much information as verbal communication.

Routines and rituals, as described by Fiese (2006), also offer a way for families to right themselves when exposed to risk (e.g., poverty, divorce). Fiese proposed that family rituals can be used to engage or disengage from the social world; thereby reinforcing the idea that routines and rituals have the potential to be helpful or harmful. Gallimore and Lopez (2002) stated that routines support daily life in critical ways, but routines can also limit daily life and hinder change. Fiese provided an example of how routines can derail family health. She proposed an instance in which a child with a chronic respiratory condition endures medical complications because his/her family will not or cannot change their smoking habits. A less obvious example could be a special dessert served at every Sunday dinner that might be detrimental to the health of a child with diabetes.

In summary, I have identified various types of family routines. Because it seems impossible to remove meaning from routines, I do not separate rituals from routines. I emphasized the idea that routines are culturally constructed and susceptible to environmental forces. These environmental forces often require that adaptations and accommodations be made, especially in families with young children and children with disabilities. Finally, I proposed benefits related to the establishment of family routines; but cautioned that in some instances, routines can also constrain daily life and derail family health.

### *Autism*

According to the National Institute of Child Health and Human Development (NICHD) (2008), “Autism is a complex developmental disability that causes problems with social interaction and communication.” Symptoms vary widely in autism and thus the term ‘autism spectrum’ is often used. Per the NICHD website, “The autism spectrum disorder category currently includes: Autistic Disorder, Asperger Syndrome, and Pervasive Developmental Not Otherwise Specified.” The

prevalence of autism has been increasing since the early 1990s (Shangraw, 2007). The Autism and Developmental Disabilities Monitoring Network of the Centers for Disease Control and Prevention (CDC) (2008) released data in 2007 that found about 1 in 150 eight-year-old children in multiple areas of the United States had an autism spectrum disorder and that boys are four times more likely to be affected than girls. While the CDC cautioned that these statistics cannot be generalized to every area of the United States, the findings demonstrated the rising prevalence of autism. According to Shangraw, autism is the third most common developmental disorder, however the reason for the increasing prevalence of autism is not known.

*Characteristics of autism.* Impairments in social interaction and communication, disturbances in behaviors (Rogers, 2005), as well as sensory processing difficulties (Baranek, Wakeford & David, 2008), which are discussed in detail in the following section, are often found in autism. Impairments in social interaction include: (a) difficulties using nonverbal behaviors, such as eye contact, facial expressions, and gestures; (b) a lack of peer relationships; (c) decreased concern for sharing or pointing out interesting objects or events; and (d) deficits in the exchange of feelings (American Psychiatric Association, 2000). Impairments in communication include: (a) language delays, (b) difficulty maintaining conversations, (c) repetitive use of language, and (d) difficulty employing pretend play or imitation of others during play (American Psychiatric Association). Restricted and stereotyped behaviors include: (a) abnormal intensity related to one's interests; (b) rigid adherence to routines and rituals, which are often not functional; (c) repetitive motor patterns; and (d) fixation with parts of an object (American Psychiatric Association). Delays in self-care abilities, such as toileting (Dalrymple & Ruble, 1992), and deficits in independence during ADL performance (Koegel, et al., 1992) have also been reported by parents of children with autism. These characteristics can negatively impact children's participation in home, school, and community activities (Rogers).

*Sensory issues in autism.* Baranek, et al. (2008) described sensory abnormalities in children with autism. According to Baranek, et al., “Research conducted with preschoolers with autism confirms higher rates of some features in autism as compared with both typically developing children and children with other developmental disabilities” (p. 107). The authors cautioned that while sensory features are not universal in autism, they appear to be highly prevalent. Baranek, David, Poe, Stone, and Watson (2006) explored two common sensory patterns – hyper- and hyporesponsiveness. The authors defined hyperresponsiveness as “an exaggerated behavioral response to sensory stimuli” and hyporesponsiveness as a “lack of response or insufficient intensity of response to sensory stimuli” (p. 591). The study found that children with autism had significantly higher sensory symptoms as compared to typically developing children or children with developmental delays based on parent report. The authors defined sensory symptoms as any individual item or feature on the Sensory Experiences Questionnaire (e.g., covers ears to sound, lacks response to pain, or watches things spin; Baranek, et al., 2006).

A higher level of hyporesponsiveness has been found in the children with autism as compared to typically developing children or children with developmental delays, while a higher level of hyperresponsiveness has been noted in children with developmental delays and children with autism as compared to typically developing children (Baranek, et al., 2006; Baranek, Boyd, Poe, David & Watson, 2007). Watling, Deitz and White (2001) found that children with autism performed differently than children without autism on eight factors of the Sensory Profile (Sensory Seeking, Emotionally Reactive, Low Endurance/Tone, Oral Sensitivity, Inattention/Distractibility, Poor Registration, Fine Motor/Perceptual, and Other). The authors also found that children with autism had scores that “spread further across possible scores ranges than the scores of children without autism, suggesting that this group may not be homogenous” (p. 419).

The differences in sensory processing of children with autism has been attributed to lower mental age (Baranek, et al., 2006, 2007), difficulty perceiving the gestalt (Baranek, et al., 2008), and/or neurological breakdowns (Baranek, et al., 2007). Baranek, et al. (2006) found that sensory

symptoms were inversely related to mental age, meaning that as a child matured sensory symptoms diminished. The authors suggested that more effective coping strategies, life experiences, and improved executive function are afforded with a higher mental age and could explain why this relationship exists. It seems possible, then, that over time children's experiences and established routines could help with their ability to handle and appropriately respond to sensory experiences.

Dunn (1997) proposed a model to explain the relationship between behavioral responses and neurological thresholds to sensory stimuli. Dunn's model contains four possible patterns that could result from this relationship: (a) poor registration, resulting from a high neurological threshold and according behavioral response; (b) sensation seeking, resulting from a high neurological threshold and counteractive behavioral response; (c) sensitivity to stimuli, resulting from a low neurological threshold and according behavioral response; and (d) sensation avoiding, resulting from a low neurological threshold and counteractive behavioral response. Alternatively, Baranek, Reinharsten, and Wannamaker (2001) proposed a dynamic model of sensory processing, in which an optimal engagement band exists between the orientation and aversion thresholds. According to Baranek, et al., below the orientation threshold a child may display no response, poor attention, and poor processing. Above the aversion threshold, Baranek, et al. contend that a child may appear inattentive, avoidant, and reject sensory stimulation. In the optimal engagement band that lies between these thresholds, a child may display positive affect, be attentive and approachable, and adequately process sensory information (Baranek, et al.). If children are able to maintain a level of sensory stimulation within the optimal engagement band, perhaps they might be better positioned to engage in family occupations.

Families are concerned with helping children to live with autism. I found at least 132 books on Amazon.com when I performed a search for 'self-help for families of children with autism.' Based on the sensory features found in children with autism to date, it appears that families are likely affected by either the symptoms of autism, in general, or, more specifically, by the sensory responses of children with autism. Families also seek out many sensory-based interventions that are not well

validated. Therefore, it is important to explore what effect children's sensory experiences have on family occupations.

### *Occupations in families of children with autism*

Before I address occupations in families of children with autism, I think it is helpful to examine existing literature about how a child with autism affects other facets of family life. Having a child with autism can place a considerable amount of stress on the family (Higgins, Bailey & Pearce, 2005). Rodrigue, Morgan and Geffken (1990) described the stress experienced by mothers of children with autism. The authors found that mothers of children with autism experienced less parenting competence, less marital satisfaction, and less family adaptability than mothers of typically developing children or children with Down's syndrome. Tunali and Power (2002) studied how mothers of children with and without autism coped with the stress of child-rearing. The authors found that mothers of children with autism spent significantly more time with their children than parents of typically developing children. Additionally, the results of their study revealed that mothers of children with autism had more difficulty understanding their child's behavior, placed less emphasis on career success and working outside of the home, and spent more leisure time with their extended family. These studies demonstrate how a child with autism can affect a mother's occupations. Additionally, since families are considered open systems (Humphry & Case-Smith, 2005), it is important to note that changes to a mother's occupations would likely have an effect on the entire family.

Larson (2006) conducted a qualitative study with mothers of children with autism to determine how children's propensity for routinization influenced participation in family activities. She found that the mothers she studied had to restructure family life due to the unpredictable and difficult behaviors of their children with autism. Specifically, Larson highlighted that the mothers she studied restructured family life by:

- (1) creating and maintaining highly structured regular family routines, often devoid of spontaneity, especially to manage basic care tasks (eating, bathing, dressing, and grooming);



(2) restricting family social events and home visitors, and keeping the social environment as predictable as possible; (3) carefully selecting family activities and organizing plans and contingencies to accommodate the child's needs in staying (or leaving the event while the family stayed); and (4) re-forming family holidays and rituals to include the child in a limited way. (p. 77)

Larson also stated, "The inability to tolerate change in weekly routines severely restricted any changes in schedules or participation in spontaneous or infrequent activities outside the home" (p. 74).

Baranek, et al. (2008) proposed that although some sensory features may not be specific to autism (e.g., hyperresponsiveness), they can have an impact on the family and their participation in the community. For example, Baranek, et al. (2007) noted that adapting to a child's response to sensory stimuli can impact the family's "number, type, or quality of shared social experiences" (p. 233). The authors also suggested that play material and/or diets could be impacted by a child's sensory experiences. In a qualitative study of children's sensory experiences Dickie, et al. (2009) found that children with autism were reported to have more extreme and/or unusual sensory experiences than typically developing peers. Additionally, the authors stated that parents of children with autism were more likely to recognize sensory aspects of everyday activities and attribute their children's responses to characteristics of autism. It is important to note that Dickie, et al. also found similarities in sensory experiences of children with autism and typically developing children. For both groups, the most common unpleasant experiences were related to sound, while the most pleasant experiences related to touch and movement.

DeGrace (2004) discussed the lack of research aimed at services for supporting occupations of families with children with autism. She suggested that interventions must focus on helping the family engage in what they need and want to do together. In her qualitative study examining everyday occupations in families of children with autism, DeGrace pointed out four key themes. She suggested that: (a) "family life revolves around autism" (p. 545), (b) the family feels robbed of satisfaction and happiness, (c) families try to "occupy and pacify" (p. 545) children with autism to help manage behaviors, and (d) there were only "fleeting moments of feeling like a family" (p. 545). This work

helped to develop a sense of how challenging everyday life can be for a family living with a child with autism. Additionally, many of the examples that DeGrace presented in her study demonstrated how sensory experiences in autism can impact daily life and family occupations. For example, DeGrace described one family who had to come home early from a beach vacation because of their child's negative emotional and behavioral responses to walking on sand and going into the ocean. On the other hand, DeGrace also described how sensory experiences can be used to affect behavior in a positive way, such as using a bath to relax a child.

Spitzer (2003) looked specifically at the definition of occupation for children with autism. She defined occupation as, "a set of directed actions connected by physical movements, materials, space, or purpose within a time period, in a way that is meaningful to the individual executing them" (p. 72-73). Spitzer suggested that a child with autism may have difficulty communicating why certain actions, such as pouring sand or dropping handfuls of dirt, might constitute an occupation or why a certain occupation is personally meaningful. Families of children with autism might find this definition of occupation helpful in reframing their beliefs about why their child with autism may have difficulty participating in or finding meaning in family occupations.

Segal (1999) suggested that the principle of commitment is an important component to finding enjoyment in occupations such as dinner time for families of children with autism when a child may be unable to verbally participate in the occupation. Segal (1999) stated:

The principle of commitment in the context of love, marriage and family means that there is an obligation to sacrifice one's needs for the well-being of other family members. The enjoyment and happiness of the individual come from the happiness and well-being of the other family members and from the practice of such occupations. (p. 6)

Gray (2006), in a longitudinal qualitative study of coping in parents of children with autism, found that parent's coping strategies changed over time. Specifically, he found that over time parents utilized fewer strategies overall. Additionally, Gray determined that "fewer parents coped through reliance on service providers, family support, social withdrawal and individualism...[and] more parents coped through their religious faith and other emotion-focused strategies" (p. 970). Gray

suggested that the change in parents' coping over time could reflect the children's long-term improvement, including the ability to create more organized habits and routinized family life or the family's access to necessary services. Gray's longitudinal findings highlight the importance of habits and routines in the daily life and occupations of families with children with autism.

Kuo, Orsmond, and Seltzer (2008) conducted a time use study for adolescents with autism. This study identified that adolescents with autism spent discretionary time most frequently engaged in watching television, using the computer, and exercising. Kuo, et al. observed that adolescents with autism also spent a considerable amount of time alone, with family, or with service providers rather than with peers. These results were part of a longitudinal study of time use patterns in people with autism. Over time decreases in social impairment were noted by the authors when an adolescent spent more time conversing with others. However, Kuo, et al. also noted that maladaptive behaviors were more common among adolescents who spent more time shopping, which is interesting considering that shopping could be a standard family occupation.

Another study conducted by Orsmond, Krauss, and Seltzer (2004) investigated participation in social and leisure activities among 235 adolescents and adults with autism. Although Orsmond, et al.'s participants were older than the participants in this study, their results are worthy of discussion. Orsmond, et al. found that more participation in social and leisure activities "was predicted by characteristics of the individual with autism...and characteristics of the environment" (p. 245). Characteristics of the individual that led to increased participation included qualities such as being more functionally independent, being more withdrawn, and having less difficulty with social interaction (Orsmond, et al.). Characteristics of environments that were conducive to participation included inclusion in school settings, increased receipt of services, and higher amounts of participation in social and leisure activities by the mother of the adolescent or adult with autism (Orsmond, et al.). Orsmond, et al.'s last finding highlights the importance of participation in family occupations. Some people with autism may be participating in more social activities with their

mothers. Alternatively, the mothers may model, and thereby facilitate, social participation for their children.

In summary, this chapter focused on three main topics: (a) family occupations, routines, and rituals; (b) characteristics of and sensory experiences in people with autism; and (c) occupations in families of children with autism. Although existing literature about family occupations, routines, and rituals helps one to understand why family occupations are important to child development, family development related to family occupations is not often examined. Existing literature also cited various types of family routines, which are culturally constructed and susceptible to environmental forces. These environmental forces often lead to accommodations, especially in families of young children with disabilities. However there is a dearth of literature that specifically addresses how children's sensory experiences affect family routines.

I have also reviewed literature on the characteristics of autism, including sensory issues in autism. Existing literature confirmed that children with autism often exhibit differences in processing and responding to sensory experiences, thus creating a need for research that helps to explicate how these sensory differences affect everyday family life. Finally, I examined existing literature on occupations in families of children with autism and provided a proposed definition of occupation for people with autism. Although these studies provided some insight into everyday life in families of children with autism, the studies have not used a comparison group of typically developing children to determine areas of overlap. Based on this review of existing literature, I noted that the specific effects of sensory experiences in the environment on family routines and occupations warranted examination.

The primary purpose of this study is to generate a grounded theory that helps to explain what effect children's sensory experiences have on family occupations. The two sub-questions I explored related to my primary purpose were: (a) What similarities and/or differences can be found among children with autism and children who are typically developing? (b) What effect do children's sensory experiences have on family routines at home and in the community?

## Chapter 3: Methods

This qualitative study, which used convenience sampling, was conducted as part of an ongoing NICHD-funded grant called the Sensory Experiences Project (<http://www.med.unc.edu/sep/>), studying sensory features in preschoolers and school-age children with and without autism. In this portion of the study, I interviewed one or both parents of children with autism and children who are typically developing, using a semi-structured interview approach. Sampling and interview strategies were selected in order to provide family-based accounts of children's sensory experiences. These parental accounts were used to develop a theory to help explain what effect children's sensory experiences have on family occupations.

### *Design*

I selected a grounded theory approach (Charmaz, 2006; Creswell, 2007; Strauss & Corbin, 1990) for this study because existing literature does not provide a theory to account for the effect of children's sensory experiences on family occupations. Theories exist to explain how: (a) context can affect an individual's occupations, (b) dynamic systems of the family impact development of the child, and (c) how children with autism process and respond to sensory stimuli. However no theories specifically addressed what effect children's sensory experiences have on family occupations or family routines at home and in the community.

Strauss and Corbin (1990) define a grounded theory as "one that is inductively derived from the study of the phenomenon it represents" (p. 23). Grounded theory research differs from other methods of qualitative inquiry in that it moves, as Creswell (2007) stated, "beyond description...to

generate or discover a theory” (p. 63). A key concept of the grounded theory approach is the generation of a theory from data collected from participants who have experienced the phenomenon of interest. Grounded theory methodology, therefore, does not begin with a theory in mind to test. As Strauss and Corbin state, “Rather, one begins with an area of study and what is relevant to that area is allowed to emerge” (p. 23).

My use of grounded theory methodology is important because I subscribe to a constructivist perspective. From this perspective, I believe it is necessary to allow a theory to arise from data rather than to test a pre-determined theory. Strauss and Corbin (1990) offered a systematic procedure for conducting grounded theory, while Charmaz (2006) provided a less prescriptive and more constructivist approach to generation of a grounded theory. I found the processes and procedures offered by Strauss and Corbin to be helpful in organizing and structuring my analysis. Yet, the grounded theory that emerged from this study is what Charmaz refers to as “an interpretive portrayal of the studied world” (p. 10). I cannot remove my experiences, knowledge, or perspective from my research and thus it is important to acknowledge that the grounded theory generated from this study is constructed through my personal lens.

Prior to conducting this research, I worked as a graduate research assistant for the larger study, helping to organize and analyze previously conducted qualitative interviews. Therefore my focus on sensory experiences in children was relevant to the bigger study and the qualitative interviews were conducted as a subset of the larger mixed methods study. In the time I spent reading previously conducted qualitative interviews, I was impressed by the differences the larger study team and I observed in children with autism’s sensory processing. Yet I noted a number of similarities between the interviews of typically developing children and children with autism that were not highlighted in existing literature. It was through this lens that I ‘constructed’ (Charmaz, 2006) my grounded theory.

### *Participants*

The participants for my study were parents of typically developing children and children with autism. I interviewed parents of 12 children – six children with autism and six typically developing children. Ten interviews were conducted with mothers. One interview was conducted with a father. One interview was conducted with both a mother and a father. With the exception of two families – one family of a child with autism and one family of a typically developing child – all families had at least one other child in addition to the child identified in this study.

Children with autism and their parents were recruited for the larger study using a university-based state-wide research registry. Typically developing subjects and their parents were recruited largely through email list-serves and word-of-mouth. Although I would have preferred to use a theoretical sampling method (Strauss & Corbin, 1990), it was difficult to obtain a homogeneous group (Creswell, 2007) of children with autism due to the wide range of the symptoms and behaviors that are included on the autism spectrum. Typically developing participants were matched to participants with autism based on gender and age. All typically developing children were within 13 months of age of the child with autism with whom they were matched.

All participants' names have been changed to protect the identity and confidentiality of the families who participated in this study. Parents of children with autism have been given names starting with the letter 'A.' Parents of children who are typically developing have been given names starting with the letter 'T.' Please see Table 1 for characteristics of the study participants.

Table 1. Study Participants

Parent Name	Participant Group	Child's Chronological Age	Child's Sex	Mother's Level of Education	Parent Name	Participant Group	Child's Chronological Age	Child's Sex	Mother's Level of Education
Amy and Aaron	Autism	2 years, 4 months	Male	High school diploma	Tara	Typically Developing	2 years, 4 months	Male	Associate degree
Adam	Autism	4 years, 7 months	Male	Graduate degree	Teresa	Typically Developing	3 years, 7 months	Male	Graduate degree
Anita	Autism	7 years, 5 months	Male	Graduate degree	Tracy	Typically Developing	7 years, 0 months	Male	Graduate degree
Amanda	Autism	7 years, 11 months	Male	High school diploma	Tiffany	Typically Developing	7 years, 2 months	Male	College degree
Allison	Autism	7 years, 11 months	Female	Graduate degree	Trina	Typically Developing	6 years, 10 months	Female	Graduate degree
Anna	Autism	8 years, 6 months	Male	Graduate degree	Tammy	Typically Developing	7 years, 6 months	Male	Associate degree
	N = 6	Mean = 77.33 months	Male = 5 Female = 1	High school diploma = 2 Graduate degree = 4		N = 6	Mean = 68.83 months	Male = 5 Female = 1	Associate degree = 2 College degree = 1 Graduate degree = 3

Both for the larger Sensory Experiences Project, as well as for this study, children met specific inclusion and exclusion criteria. In order for the children to be included in the autism group, they must have a diagnosis of Autistic Disorder, Asperger Disorder, or Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) from a licensed psychologist or physician. The diagnosis must be confirmed by the child's performance on the Autism Diagnostic Interview -



Revised (Lord, Rutter, & LeCouteur, 1994), Autism Diagnostic Observation Schedule (Lord, Rutter, Dilavore, & Risi, 1999), and the expert clinical impression of the Sensory Experiences Project staff, based on the criteria for Autistic Disorder in the Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV) (American Psychiatric Association, 2000).

According to the DSM-IV (American Psychiatric Association, 2000) all people diagnosed as having Autistic Disorder exhibit qualitative impairment in social interaction and/or communication, as well as restricted repetitive and stereotyped patterns of behavior, interests, and activities. Autism can also be diagnosed based on, “delays or abnormal functioning in at least one of the following areas, with onset prior to three years of age: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play” (p. 69). All children within the autism group for this study were classified as having Autistic Disorder by the larger study team.

Children were included in the typically developing group based on parent report as documented via the PEDS questionnaire (Glascoe, 2000). Children were excluded from the typically developing group if the parents expressed concern over developmental delays or if the child had a history of, or was receiving treatment for, developmental or behavioral concerns. Children were excluded from the study if they had any co-morbid conditions associated with autism (e.g., Fragile X syndrome) or seizure disorders as confirmed by medical records. Children were also excluded from the study if their hearing and visual acuity could not be corrected to within normal limits or if they were non-ambulatory or had significant physical impairments. The families of children with autism received a monetary incentive (\$25 to \$75, dependent upon their child’s age and diagnostic status) for their participation in the larger study. The children received a small toy or book. Parents of typically developing children received \$5 for completing the qualitative interview. This study was approved by the University of North Carolina at Chapel Hill Institutional Review Board. Informed consent was obtained from the parents who participated.

### *Data collection*

I conducted telephone or face-to-face interviews with parents, depending upon the preferences and availability of the interviewee. Data collection took place over a 6-month period. The interview consisted of a series of questions and associated prompts and probes that were agreed upon by the study team. Prompts helped provide an example of the type of incident I sought to examine. For example, prompts were used to help the parent understand what might be considered sensory or what certain behaviors might look like. Prompts were only used when necessary. Probes sought to elicit contextual elements of the experience (e.g., Who was around when this experience occurred? Where did it occur? How did you know it was something the child enjoyed/disliked?). The probes also served as a method of validation as they helped to clarify my understanding of the interviewees' statements (M. Sandelowski, personal communication, September 10, 2008).

*Interview Script.* A series of open-ended questions were posed to the interviewee. First the parent was asked to describe an incident during which the child seemed to have a good sensory experience, then to tell why he or she thought it had been a good experience for the child, and last to explain how it had made the parent feel. The same set of questions was then asked with respect to a bad or unpleasant sensory experience. Next, the interviewees were asked to identify examples of times when their child exhibited specific responses to sensory experiences. For example, a parent was asked to describe a time when a child responded strongly to a sensory experience or did not respond to a sensory experience. The parents were then asked to tell the interviewer about routine events in their households and what meaning these events held for their families. Next the parents were asked how things done as a family were affected by their child's sensory experiences. Finally, the parents were asked to describe how their child's sensory experiences have changed the way they experience the world. Please see the Appendix for a full copy of the interview script I used.

*Critical Incident Technique.* The semi-structured interview conducted with one or both parents consisted of open-ended questions based on Flanagan's Critical Incident Technique (CIT) (1954). Although the CIT was originally developed for use in quantitative studies, it has been successfully adapted for use in qualitative work (e.g., Dickie, et al., 2009; Hasselkus & Dickie, 1994). Flanagan defines critical incidents as, "extreme behavior, either outstandingly effective or ineffective with respect to attaining the general aims of the activity" (p. 338). According to Flanagan, the use of extremes of behavior is efficient. He states, "It is well known that extreme incidents can be more accurately identified than behavior which is more nearly average in character." According to Dickie, et al., the CIT method "permits deeper analysis of subgroups of subject responses." This method of data collection is extremely useful in a grounded theory study because, as Dickie, et al. pointed out, "The advantages of this method of data collection are its focus on the specific phenomenon of interest, the gathering of concrete examples of behavior, its flexibility, and the ease of use with a relatively large number of subjects." The CIT (Flanagan) elicited specific phenomena and provided data with what Strauss and Corbin refer to as proven theoretical relevance (1990).

### *Data analysis*

All interviews were audio recorded and transcribed verbatim. I reviewed each transcription for accuracy against the original interview recording to provide reliability. I utilized the Atlas.ti software program (Muhr, 2004) to facilitate my qualitative analysis and organize my data. To validate my findings, I clarified interviewees' statement throughout the interviews (M. Sandelowski, personal communication, September 10, 2008) and performed multiple readings of the transcribed interviews. I also participated in peer debriefing (Creswell, 2007) with my research advisor and other colleagues. Theoretical saturation occurred when, as Strauss and Corbin (1990) suggested: (a) no new data arose that contributed category development, (b) categories were densely developed to account for all

elements of the paradigm, and (c) the relationships between categories were well-established and supported by the data. Existing literature helped me to situate the findings (Strauss & Corbin).

I used the grounded theory coding techniques of open, axial, and selective coding during data analysis (Creswell, 2007; Strauss & Corbin, 1990). During open coding I identified and developed concepts and categories, which Strauss and Corbin suggested are the “basic building blocks of theory” (p. 74). I labeled incidents captured in the interviews on a detailed line-by-line basis, constantly comparing incidents described by the participants to develop a comprehensive list of codes. Open codes included the type of sensory input (e.g., sound, movement, touch), whether the experience was positive or negative for the child, and aspects of the child’s reaction to the sensory experience (e.g., laughing, scared, covers ears, runs away). There were also codes that captured specific routines or occupations (e.g., bedtime, bathtime, reading, exercise), as well as codes that described the effects of the child’s sensory experiences on the family (e.g., parent feels frustrated, preparation/planning increased, parent educating self). A total of 110 codes were created during open coding.

Relationships between the concepts and categories I created in open coding were developed during axial coding using Strauss and Corbin’s paradigm model. During axial coding I grouped each of my open codes under one of the following headings: causal conditions, phenomenon, context, intervening conditions, action/interaction strategies, and/or consequences. This allowed me to develop relationships between codes and identify emerging constructs. For example, causal conditions included codes describing types of sensory input and the environment (e.g., new versus familiar environments). The phenomenon included the type of response (e.g., positive, negative), the behaviors exhibited (e.g., seeking, hyper-response, hypo-response), and child reactions. Reactions included emotional reactions such as ‘scared’ or ‘irritated,’ physical reactions such as ‘covers ears,’ and a combination of reactions such as ‘intensity’ and ‘verbalizes feelings or wants.’ Categories under the context heading included specific family routines and occupations, as well as who participated in the occupation or routine with the child (e.g., dad, siblings) and where the occupation or routine took

place. Codes grouped under the intervening conditions heading included labels such as ‘public perception,’ ‘family time/togetherness,’ and ‘therapists,’ which was a code used to capture when parents made reference to therapy or therapists.

The heading of action/interaction strategies included codes that captured how the family attempted to handle the child’s response to a sensory experience such as ‘accommodation,’ ‘parent feels inadequate,’ and ‘planning/preparation increased.’ Lastly, codes describing family effects, parent feelings, and parent effects were captured under the consequences heading. Codes in the ‘family effects’ category included things like ‘leave early’ and ‘social participation effect.’ Codes in the ‘parent feelings’ category included ‘frustrated’ and ‘parent feels inadequate/unable to help.’ The ‘parent effects’ category included codes such as ‘parent educating self’ and ‘aware of little things.’ Once all open codes were grouped into axial categories under these six headings, I was able to identify trends between the groups. The groupings also enabled me to identify codes and categories with theoretical relevance (Strauss & Corbin, 1990), as noted by their distinct presence or absence across multiple interviews. For example, the presence of distinct family routines, such as mealtime, bedtime, and bathtime were noticeably present in all interviews, whereas the parental feelings of confusion and the extensive planning and preparation required for some family occupations were present in the autism group, but noticeably absent from the typically developing group.

Selective coding is the highest level of coding, during which I created three core categories that capture what Strauss and Corbin refer to as “the central phenomenon” (p. 116). I used a memo technique (Charmaz, 2006) and peer debriefing to identify these selective codes, which related my categories to core themes and to each other (Strauss & Corbin). Using the memo technique (Charmaz), I captured my thoughts about potential emerging themes, labeled interesting quotes from parents, and identified qualities about the interviews such as the speed and ease with which parents of children with autism were able to provide examples of sensory experiences.

I utilized constant comparison methodology (Schwandt, 2007) during axial and selective coding to develop a tentative theory from the transcribed interviews. Consistent with the constant

comparison methodology I compared and contrasted data assigned to particular codes and concepts to: (a) refine concepts and codes, (b) create new concepts or relationships, and (c) validate my theoretical propositions. To validate my findings, I clarified interviewees' statements throughout the interviews and read the transcribed interviews multiple times prior to and during the coding process. I read each transcription in its entirety prior to coding. I also took field notes throughout my data collection, wrote field notes after parent interviews, journaled during the coding process, and participated in peer debriefing with my research advisor. These validation techniques allowed me to initially identify and, ultimately, clarify and crystallize my three themes.

These coding techniques allowed me to develop a theory grounded in the data provided by the parents I interviewed that helped to explain what effect children's sensory experiences have on family occupations. The grounded theory coding methodology also allowed me to keep my sub-questions with regard to family routines at home and in the community and similarities and differences among the groups in mind during the coding process. I identified three themes that help to explain how children's sensory experiences affect family occupations. Children's sensory experiences affect: (a) what a family chooses to do or not do; (b) how the family prepares; and (c) the extent to which experiences, meaning, and feelings are shared.

## Chapter 4: Findings

My results are organized into three themes that construct a grounded theory. These themes explain how children's sensory experiences affect family occupations, including those occupations performed at home and in the community. Within each theme I highlight similarities I identified between the families of typically developing children and families of children with autism. I also note some differences I identified between the groups. Statements from parent interviews are included to support each of my identified themes. (Note the first letter of each parent's name represents the group to which his or her child belongs – i.e., parent names starting with 'T' represent the parent of a child who is typically developing, while parent names starting with 'A' represent the parent of a child with autism.) Based on this study, I determined that children's sensory experiences affect: (a) what a family chooses to do or not do; (b) how the family prepares; and (c) the extent to which experiences, meaning, and feelings are shared.

### *What the family chooses to do or not do*

Children's sensory experiences affect which occupations families choose to participate in and which occupations families choose to avoid. Four subthemes emerged in this area: (a) everyday family routines are powerful, (b) getting the energy out is important, (c) social participation is affected by children's sensory experiences, and (d) families choose to seek out or avoid certain sensory environments for their children.

*Everyday routines are powerful.* First and foremost, the parent interviews highlighted the power of everyday family routines. Each parent I interviewed identified specific, meaningful family routines. Bedtime, mealtime, and bathtime were the most commonly mentioned meaningful family routines. These routines were consistently mentioned by parents of both typically developing children and children with autism. Tracy described bedtime as, “kind of a quiet time that we get to spend with him...a time where we can actually, you know, enjoy what’s going on, because there’s not usually any rush to get anywhere or get something done.” Trina described the calming nature of the family’s bedtime and bathtime routines when she said, “It’s our way of taking it down a notch...[Bathtime]’s kind of that break. Okay, we’re *done* being crazy busy. Now we’re gonna get our bath...[and] our jammies on.” Amy confirmed the calming, intimate nature of bedtime routines as she stated, “I always have to trace his back and belly. I don’t know why, it just calms him down and gets him quiet and you know he drifts off to sleep that way.”

Adam described the importance of family togetherness during the bedtime routine when he said:

During weekdays we don’t see [the children] very much, because they go to school and then we teach in the afternoon. So the late evening - 8 to 9 o’clock - is very special because that’s what we have...it’s difficult, but it’s very special, because it’s so limited.

Family togetherness was also noted during parents’ description of mealtime routines, although parents of typically developing children tended to describe mealtime as a meaningful event more frequently than parents of children with autism. Teresa stated, “I think one of the most meaningful events is dinner time for us... It’s something we do as a family. And we value that – that we’re all including one another.” Another mother, Tiffany, stated that mealtime was meaningful because of the conversation that occurred around the table saying, “...just having the opportunity to all be together in one place and talk about your day, what are you thinking about, anything...just have that conversation.”

Bathtime tended to be important to some parents of children with autism and typically developing participants due to the enjoyment the children derived from the bath experience. Adam



speculated about why his son enjoyed bathtime. He stated, “I don’t know whether it’s the temperature or whether it’s the feeling of the water flowing around him, or just being relaxed and comfortable, or a combination of those things. But he *really, really* enjoyed it.” Similarly, Trina described the positive sensory aspects of bathtime when she stated, “I think it’s quiet. I think it’s the movement of the water and the temperature of the water. And I think it’s the weight of the water also.”

Bathtime also represented a form of social engagement. For example, Amy described how her son’s older sister enjoyed helping give her brother a bath. Tara described how her child enjoyed time with his dad during bathtime. Tara also mentioned that her son enjoyed it when she and her husband began playing an impromptu game of catch with a squishy ball during bathtime. Parents of children with autism also mentioned specific toys used at bathtime. Amanda described how her son enjoyed playing with color tablets, while Amy described how her son disliked the use of foam soap, which she tried after reading about it in a book for parents of children with sensory dysfunction.

*Getting the energy out.* Parents of both typically developing children and children with autism described the importance of sensory stimulation from physical activity. The parents often described the importance of “getting the child’s energy out” through hiking, swimming, going to a playground or gym, or through rough play. Anna explained how her family began taking hikes together because of the benefits they derived from physical activity. She stated, “A *huge* part of our lives is trail walks, bike rides, swimming. Just we get a *tremendous* amount of exercise... We are the most ourselves, all of us, whenever we are on a trail walk together.” She went on to describe how “organized” her son became after “a *really vigorous* workout” and compared it to how she might feel after a day of skiing. Similarly, Tracy described how good her son felt after playing basketball and, conversely, how difficult it can be for him to focus if he has not had enough exercise. She stated:

I’m glad he’s getting his energy out. And I’m glad it works for him...as something he can do before he has to sit and do something else. On the other hand, it can be kind of frustrating because if he doesn’t get it out and he still has to do those activities - it can be a challenge.

Three other mothers of typically developing boys noted the importance of participating in physical activity at a local YMCA or gymnastics class. Tara said, “We have started going to our local Y a lot more and using the gymnastics room. So he can go...on the trampoline and use the parachute and the big balls to get some of his energy out.” Two other mothers of typically developing boys noted their sons’ attendance at local gymnastics classes. Teresa stated, “It’s really helping him to improve his gross motor skills.” Tiffany described how proud her son was to improve his cartwheel and forward somersault.

The parents of children with autism tended to highlight more social and sensory aspects of physical activity. For example, Anita described how much her son enjoyed swimming with his father. She also mentioned the potential future benefits of continued participation in swimming when she stated:

I feel it’s something that could be almost a savior for him, because he’s not into sports so much. But that would be his sort of, you know, escape... ‘I need exercise’ and he would know exactly what to do. So I feel that moving forward, that could be his sport. You know, something that he could take up. And, you know, it would give him self-esteem as he starts doing well in it and things like that.

Allison described how her daughter enjoyed rough play with her sister, by saying, “They seem to both be enjoying that physical kind of... you know, rolling around on the floor together.” Similarly, Aaron and Anna described how their sons enjoyed wrestling with their fathers. Anna stated why she felt the physical activity between her husband and son was important when she said, “It’s one of *my* favorite times of day, because I just like listening to them. You know? So I think it’s an important time for father-son bonding and it’s also really good physical input.”

Amanda explained that her son enjoyed jumping on the trampoline with his older brother and his brother’s friends. She stated, “It gets out his extra energy. It actually *calms him down*. It’s enough stimulus to where he’s puttin’ out a lot of energy to get something back. And he likes the reward.”

Amy described how her son seemed to “be a lot better outside” where she could let him run and climb. She also highlighted her son’s enjoyment of the sensory components of outdoor play when she

said, “He would rather stomp around and listen to the different sounds underneath his feet than he would go play on the jungle gym or go play on the swing set or anything like that.”

*Effects on social participation.* Both groups of parents identified ways in which their children’s sensory experiences affected their families’ social participation. Social participation was an aspect of family occupations that differed considerably between families of typically developing children and children with autism. The parents of children with autism tended to limit or avoid particular places or situations due to their children’s sensitivity to sensory experiences, while the parents of typically developing children commonly emphasized the opportunities that opened to the family because of children’s enjoyment of sensory experiences.

Amy described how she had difficulty attending an outdoor wedding due to her son’s responses to sensory stimulation saying, “It kind of makes us want to...not attend as many social functions as we normally would have.” Another mother, Anna, explained that the family limited evening activities with other people. She stated:

He ...works very hard during the day to stay focused and to do his jobs, and to keep it together... All the things he’s coping with everyday that are so much more than we could ever imagine - he’s wiped out at night... He doesn’t stay up late. He just can’t do it. And so we can’t do a lot of things that people do with their 8-year-old kids at night. Most kids find it exciting to stay up. If you want to do fireworks, if you want to do an evening concert or whatever, we cannot... We’re not gonna stretch him so that he’s frayed. So we don’t go to places like that. We don’t stay out late. We can’t...

Anna also listed specific places that the family does not go, such as bowling alleys or loud, chaotic facilities designed for children (e.g., Chuck E. Cheese, Pump It Up), which sometime prevent her son from participating in birthday parties or other social gatherings with peers.

Allison described how the family avoided a school outing at the baseball park because her daughter disliked the loudspeakers. She also described how the family avoided the amusement park at the state fair because of her daughter’s past response to that particular sensory experience. Another mother, Anita, described specific sensory aspects of a graduation party, including the noise of people

cross-talking and loud music, as well as her son's distaste for the food choices available, which caused her family to leave earlier than they would have liked.

Some parents of typically developing children also mentioned avoiding or limiting their time in loud environments. Often the parents described the child's self-regulation strategies in loud places, such as school or sporting events. For example, Tracy noted that, "I know at school...he'll go to the quiet place and read a book or to the reading center when it just gets too much for him." Teresa stated, "If it's overwhelming to him...he tends to go sit by himself for a few minutes. But normally he'll snap out of that after five minutes or so and join the rest of the group." Tiffany provided a different reason for her family's avoidance of loud environments. She described how her husband's concern over hearing loss caused the family to limit their exposure loud noises, which prevented them from going to the movies.

A few parents of children with autism cited positive aspects of their children's sensory responses that facilitate social participation. For example, one mother described how her son enjoys touching animals and often requests to go to a local petting zoo with a friend. Another mother described how her son liked riding in a golf cart with his grandfather each year on the annual family vacation. Amanda and Anna described how their sons were "troopers" and "resilient" with regard to dealing with sensory experiences during family occupations like beach vacations, camping, and visits to amusement parks. Amanda stated, "We just try new things. We try to do everything that we could possibly...what a normal family would do."

Parents of typically developing children often explained how their children's enjoyment of various sensory experiences created more opportunities for the families, including more opportunities for socialization. For example, Teresa described how her child's love of movement and sound, in addition to his sociability, facilitated their participation in music and gymnastics classes. Tara described how her son's enjoyment of working with messy art materials made craft time at his daycare his favorite portion of the day. Other mothers of typically developing children described how their children enjoyed playing in mud after a rainstorm with neighborhood friends. Trina summarized

these sentiments nicely when she said, “The fact that her sensory experiences are normal, or even good, it opens up lots of opportunities...she’ll try anything.”

*Exposure or avoidance.* Family occupations are affected by the extent to which families are willing to expose children to stimulating sensory experiences. On the other hand, family occupations are also affected by sensory experiences that the families avoid. In this study, the families with younger typically developing children and children with autism tended to avoid particular sensory environments. Alternatively, parents of older typically developing children and a few older children with autism purposely exposed their children to stimulating sensory environments in hopes of the children developing independent problem-solving strategies and coping skills.

Parents of some younger typically developing children and children with autism tended to avoid certain sensory environments. It appeared that families chose to avoid particular situations if the child had a negative sensory experience in a similar situation in the past. Families also avoided sensory-laden situations when the parents predicted a bad sensory experience. For example, Allison stated, “The ball park- well, we just wouldn’t go there together...or...an amusement park. There are certain things that I just would avoid because...we don’t need to put her through that... That’s not fun for everybody then.” Anita said, “If it’s not a place where I think he’s going to be comfortable, I think we almost try and avoid it.” Another mother, Anna, described why she will not take her son to birthday parties at bowling alleys or overstimulating environments like Chuck E. Cheese when she said, “It’s too much and it’ll be miserable. So I learned a long time ago, why would I put him in a situation like that...to set him up to fail? I just won’t do it.” Tara, the mother of a typically developing 2-year-old boy, also described family occupations they avoid, such as grocery shopping and eating at restaurants, because of her son’s propensity “to explore a little bit too much.” Another mother, Teresa, who has a 3-year-old boy, said that she avoids cooking spicy foods for her son because of his negative sensory experiences related to that particular taste.

It appeared that parents of children with autism often avoided situations with potential for negative sensory experiences because of the difficulty in teaching coping skills. Adam described the difficulties the family experiences when they try to take their 4-year-old boy with autism into an overwhelming sensory environment. He stated, “[W]e can’t console him. We can’t reason with him. We can’t, you know, do the things that parents can normally do to calm their children or to reassure them.” Anita described how it has become easier to teach her son coping strategies now that he is older saying:

So typically he tends to want to...switch off when something overwhelms him. I guess he’s not old enough to just, say, walk away from there... We’re teaching him to sort of take a break now... But for the longest time I don’t think he even understood that it was causing him to behave... So now he’s able to articulate.

The parents of older typically developing children and some parents of older children with autism intentionally expose their children to stimulating sensory environments to develop independent problem-solving strategies and coping skills. For example, Tracy, the mother of a typically developing 7-year-old boy, said:

I mean, it’s hard. I definitely don’t want him to [have negative sensory experiences]. But on the other hand, you know, he’s gonna have to learn to deal with it. So it’s kind of a double-sided thing. Like I don’t want him to be upset and, on the other hand, I think it’s almost more important that he has a mechanism or coping skill to...be able to figure out how to deal with it. So I don’t usually try and interfere...unless it gets really extreme and then I remove him. But then he doesn’t have extreme...reactions to it, so I usually just let him figure out what he needs to do.

These parents tended to express frustration with their children’s negative sensory experiences.

Tiffany, another mother of a typically developing 7-year-old boy, stated, “It can be frustrating because...I feel like [he] overreacts about a lot of things... But I also think...we have to think of strategies to help with that.” Trina, the mother of a typically developing 6-year-old girl, explained, “[S]ometimes I want her to just tolerate, and desensitize herself to it...so she doesn’t become a wimpy adult that can’t tolerate anything. But if it’s really bad then I’m supportive of her finding an alternative solution.”

Anita, the mother of a 7-year-old boy with autism described the importance of exposing her son to stimulating sensory environments and creating positive experiences in hopes of future enjoyment of such experiences. She said, “[W]e feel that if there is persistent effort or, you know, positive experiences created for him, he will start enjoying some of those things at some point.” Two other parents of 7 and 8-year old children with autism explained the personal significance of exposing their children to new situations so as not to let autism dictate what the families can and cannot do and to foster a sense of resilience in the children. Anna explained:

[T]hough he thrives on routine and predictability, he is resilient. You can take him to different environments. We’ve have flown on airplanes. We’ve been to Guatemala... You can change everything up on him...the food, the bedtime, the mealtimes...and he’s okay... He’s really quite resilient as long as he feels safe. You know? And he feels safest with us.

*How the family prepares: Executing plan B...or C or D*

Children’s sensory experiences also affect the way families prepare for certain occupations, especially those with strong sensory components. Parents of both typically developing children and children with autism described how planning and preparation increased for some family occupations. Amy stated, “I guess it’s changed our perspective on just, you know, ‘Let’s just go do this.’ ‘Cause we can’t, ‘Let’s just go do this.’ We’ve got to make sure we’ve got the stroller, a bag of toys.” Similarly, Tammy noted items she would need to plan to take along when hiking because of her son’s enjoyment of exploring sensory experiences in nature, laughingly saying, “I would know I would have to pack extra clothing – automatically.” She also explained that she would need to be prepared to stop early if her son became tired after “throw[ing] himself into outdoor activities.”

Mealtime often required increased planning in families of typically developing children. For example, Teresa, the mother of the boy who disliked spicy foods, described how she made quesadillas for her son on family chili night. Teresa also described how she verbally warned her son before using the food processor during meal preparation, since he disliked the loud noise the appliance made. She described how the warning gave him time to plug his ears or run to the next room. Another mother,

Tiffany, described how she had to give her son a wet paper towel each morning at breakfast because he disliked the sticky feeling of syrup of his hands.

Tracy described how the family would occasionally leave a little early from basketball games when the buzzer was bothersome to her son. Yet she explained that as her son grew older this had become less of an issue. Aaron made an interesting point in saying that sometimes no amount of preparation can ensure a plan goes perfectly regardless of whether a child has special needs. He said, “There’s nothing you can plan out with him because it could just change. But I think that’s the way it is with every two year old.”

I noted, however, that the amount of preparation and the number of alternate plans was higher for parents of children with autism. Adam stated, “*Everything* is affected. Where we go, how we prepare to go there, what we do once we get there is affected. We always have to be aware of how [he]’s gonna react.” Anita described that her family had a number of plans in place to help her son tolerate his brother’s violin practice. Alternate plans included decisions about which family members would attend recitals and practice at the music studio, as well as thoughtful planning of the family’s day so that her son with autism could be engaged in an activity in another part of the house during his brother’s practice time at home. Anita also described how the family often planned exit strategies ahead of time when going to parties or events with a plethora of sensory experiences such as weddings or graduation parties.

Allison stated that the family would need to carefully plan where they would sit prior to attending an outdoor concert, in order for her daughter to be able to successfully participate in the family occupation. A more extreme example of alternative plans was provided by Anna, who explained that her son had a very difficult time functioning in a public school environment. The bombardment of sensory experiences and his need for frequent physical activity led to the family’s decision to home-school their son. With regard to his performance in a public school first grade class while trying to contend with everyday sensations in the classroom, such as noises, touch, and smells, she stated:



He turned into this kid that was almost like this, you know, classic autism person who like can't hear a word you're saying and cannot respond to you. When he had been this like you know functioning beautifully, totally self-sufficient, like fully integrated into the life of his classroom...in preschool, you know, with typically developing peers. But the jump from preschool to public school first grade...was way too much. The demand was just so much higher socially and academically. So I've seen him when he's overloaded and it's awful. He can't sleep... He loses body awareness. He starts having accidents. I mean it's pretty scary when he's really anxious, really overwhelmed.

Mealtime also required increased planning for the parents of children with autism, even more so than the parents of typically developing children. A number of parents of children with autism explained how their children were on modified or restricted diets, thereby accounting for some of the increased planning. Amanda described the family's detailed meal planning strategy:

[W]e have a big white board in our kitchen... And we annotate everything he eats for the whole month. We have a four week schedule. And we try to make sure he doesn't eat the same thing within a four day period. And each week we try to implement something new.

Amanda also described how her son would only eat certain shapes of pasta, so she would often make her son one type of pasta at dinner and another type of pasta for the rest of the family. This more extensive type of accommodation was far more common in the parents of children with autism.

*The extent to which experiences, meaning, and feelings are shared: A meeting of the minds...or lack thereof*

In this study I found that children's sensory experiences can also affect the extent to which experiences, meaning, and feelings are shared during family occupations. First of all, I found that family occupations generated feelings for both parents of typically developing children and children with autism. Many times these feelings were positive, leading to a sense of togetherness or the creation of memories. Parents spoke of the preciousness and rarity of family time. Allison stated that her husband worked long hours, so the time they spent reading as a family in the evenings was a special event, especially since all four members of the family enjoyed the occupation of reading. A few parents of both typically developing children and children with autism talked about the

significance of annual vacations or visits with out-of-town extended family, which usually included physical activities like going to a water park, hiking, swimming, or playing in the snow.

Other parents in both groups described how children's sensory experiences can often lead to the creation memories. Adam provided a detailed account of his family playing outside in the rain on a warm summer day. He described the utter enjoyment his son derived from the experience, saying the experience provided "memories that stick with you." Tara described how her son loves to make a mess of the ingredients while cooking with her. Despite her frustration over the mess she said, "From *my* point of view, being the mom, they grow up so darn fast... I have to step back and think, he's two, he's enjoying himself, and we're spending time together... It's a memory that we'll always have together."

Parents of typically developing children and a few older children with autism emphasized the importance of discussing feelings about or reactions to sensory experiences. Parents of typically developing children often commented that during a negative sensory experience their children would verbalize or provide non-verbal cues as to how they were feeling. For example, in response to a loud noise, parents often described how their children would cover their ears, make a facial expression, or say, "Too loud!" In response to her son's negative sensory experiences, Teresa described how she tries "to process it with him and ask him what's going on and why is he feeling [that] way."

Anna, whose son is 8-years-old, described a different kind of exchange she had with her son after a day at an outdoor camp. She stated:

He didn't even greet me when he walked in the door. He walked...straight to his work table and started coloring like really intensely. And he just colored for like a half an hour. And then half an hour later, he was settling in and we were getting ready to watch a video. And he announces to me, "I had a great day, Mom."

Anita, the mother of a 7-year-old boy with autism, described how her son had learned to tell his parents when loud noises hurt his ears. She explained the "sense of relief" she and her family felt after identifying that particular sensory experiences could "result in certain behaviors." She went on to

say, “And we also feel encouraged because he’s showing...signs that there’s a way to sort of moderate how much of this affects him.”

On the other hand, some parents of children with autism described how families sometimes do not experience the same occupation together, either because the child with autism does not participate or because the family splits during certain occupations, such as sporting events and parties. Dividing the family during particular occupations precludes the opportunity for shared experiences. Amy and Aaron described how they would play games with their older children, while trying to keep their two-year-old son with autism busy with blocks nearby. Anita stated, “There are things that we don’t do together - all 4 of us. We kind of split...” Sometimes parents view these situations as opportunities for certain members of the family to bond. For example, Allison said, “She doesn’t go to the ball park. It actually worked out well last year. We got free tickets...and her younger sister went with her dad as like a little date. And she and I did something else.”

*A meeting of minds.* In addition to the lack of shared experiences during family occupations, parents of children with autism commonly exhibited more negative feelings of confusion, incompetency, and worry. In a study of people with dementia and their day-care staff, Hasselkus (1998) proposed that in order for engagement in occupation to occur, a “cognitive connection” (p. 426) must exist between the person with dementia and the staff member. Hasselkus called this phenomenon “a meeting of minds” (p. 426). I contend that this same phenomenon can help to explain the difference between the shared experiences during family occupations. From the data in this study, it appeared that parents of children with autism had a difficult time forming that cognitive connection that enables mutual engagement in occupation.

The lack of a meeting of the minds (Hasselkus, 1998) could help families and service providers understand the difficulties in creating shared experiences, feelings, and meaning during family occupations and the resulting worry and fear parents of children with autism often seem to feel. Sometimes parents described concerns over their child’s nutritional intake related to sensory

experiences. Amanda said, “We’ve actually gotten used to that fact that he won’t eat certain foods... I just want him to be able to get all the vitamins and nutrition that he needs from what he’s eating now.” Amy described how she “took it personally” when her son disliked bath foam that had been recommended for children with sensory processing issues. The boy’s father, Aaron, described his time at home with his son saying, “There was nothing I could do...without having to worry about where he was.”

Other parents of children with autism described pervasive feelings of fear and concern regarding their child’s well-being as well as the family’s worries about the future. Allison described the pressure she placed on herself to achieve the correct balance in her daughter’s highly tailored diet and how it hurt her to see her daughter having a negative sensory experience. She stated, “I know I have some control biomedically... It’s like, ‘Oh, what am I doing wrong?’ ... I’d like her to be comfortable, while I’m getting her body to like function and work towards normal... Sometimes I’m like, ‘Aaah!’” Anna, the mother who home-schooled her son with autism described his time in the public school saying:

I don’t know how I lived through that year, knowing that he was frightened and in a bad place every single day. It was like a waking nightmare ‘cause there was like no end in sight. No matter what we did we couldn’t fix it... It was very, very stressful for my husband and I both.

Aaron explained that sensory experiences that occurred in the home were more tolerable and manageable, but dealing with his son’s sensory experiences in public was more challenging. He said, “We feel bad for us. We feel embarrassed for him, but we feel like, you know, this is just the way he is. If you can’t accept that...then you can’t accept us kind of thing.” Adam expressed his concern for the future, saying:

Whenever he’s upset, he can’t communicate, he’s frustrated... You work hard not to think too much about it. But it’s very easy to get depressed and dismayed...just wonder are we ever going to- is he ever going to have a normal life? What’s his future going to be like? It’s not just, “Oh he’s having a bad day or he’s having a bad moment. What can we do to make it better?” It’s...we need to change the situation to make him comfortable. But gosh, are we going to have to deal with this forever? Are we going to have a 30-year old child?

*Searching for the key.* Hasselkus' 1998 study can also help to explain another subtheme noted in this study. In an effort to create a "meeting of minds" (p. 426), Hasselkus described how staff often searched for the key to reach the mind of the person with dementia. Although dementia and autism are distinctly different conditions, this metaphor created by Hasselkus is applicable to this study. I found that the parents of children with autism seemed to be constantly "searching for the key" to create a shared experience. Parents of children with autism mentioned a myriad of ways in which they search for keys. Every parent of a child with autism mentioned some method he or she used to try to create a mutual engagement in occupation.

Many parents mentioned the use of other people, namely therapists, as one way to better understand their children and interpret their children's behaviors. For example, Anna stated, "And we had this phenomenal OT... And she really like explained him to us. You know, we didn't know anything about it... All this behavior explained was like incredible." Amy explained how her son's therapists helped her to engage her son in play, because she did not "know to do that." Another mother, Amanda, described how therapists explained the significance of mealtime routines, which led she and her husband to make a significant effort to engage their son with autism in dinner time with the family. Anita had a very difficult time explaining what her child might be feeling during sensory experiences. She mentioned that her husband would have been better to answer the question because, "He always has these great sort of, you know, pictures. Because...he's almost able to articulate...kind of see through [the child]'s lens."

Parents of children with autism also referred to books and conferences in an effort to educate themselves on what might help their children or to better understand what their children might be experiencing. Two parents of children with autism named specific books they had read to generate ideas for activities they could do with children with sensory processing disorders. Amanda, the mother who mentioned the white board in her kitchen stated, "I've read a lot of books about if you let an autistic child eat what he wants, their menu is going to get smaller and smaller... [W]e don't want that to happen...so we try to keep a variety." Amanda went on to describe how she has finally taught

her son to say no when the family asked him to eat a food he disliked, rather than vomit like he did in the past. When asked about what she thought her son was feeling that made him react in such an extreme way, she responded, “I’m not exactly sure. If I knew that I probably would be able to get him to eat a lot more.” This statement seems to reflect the lack of a meeting of the minds (Hasselkus, 1998). One mother even disclosed that she wrote a chapter in a book for parents to help share her experiences with others. In regard to her search for the key, she said, “I read [books]. And then I went to some conferences. I just got educated.”

A few parents of children with autism also mentioned tailored diets as a way in which they search to help their children. Adam stated that his son was on a “very restricted diet.” The boy’s diet affected how the family planned meals on vacations and even affected daily outings like running errands. The father went on to explain that when his son ate a food outside of his diet the whole family would be affected because the boy would be wide awake in the middle of the night and could stay awake for over 12 hours. Allison noted that she saw less sensory seeking in her daughter after the girl’s diet was altered. She described a specific diet protocol to which they adhered and made targeted changes to her daughter’s diet based on her genetic profile. These examples help to demonstrate the lengths to which parents will go in an effort to find ‘the key.’

## Chapter 5: Discussion

The results of this study indicate that children's sensory experiences affect family occupations. My grounded theory approach to qualitative analysis led to the identification of three main ways in which children's sensory experiences affect family occupations. Children's sensory experiences affect: (a) what the family chooses to do or not; (b) how the family prepares; and (c) the extent to which experiences, meaning, and feelings are shared during a family occupation. These findings are relatively consistent with the existing literature on the topics of family routines and occupations, occupations in children with autism, and sensory experiences in children with autism. However this study differs from most other studies that compare children with autism to typically developing children because it highlights the many similarities between the participants in both groups.

Families choose to engage in meaningful family routines, which become very powerful over time. I especially noted the significance of bedtime, bathtime, and mealtime routines. The power of these everyday routines is supported by the findings of Evans and Rodger (2008). This finding is also consistent with literature by Humphry and Case-Smith (2005), Kellgrew (2000), and Crowe (2002), who provide culturally-influenced examples of family routines. Additionally, this finding supports my point that routines can be meaningful, regardless of whether they have evolved to the level of rituals (Evans & Rodger; Fiese, 2006; Segal, 2004).

Both families of typically developing children and children with autism make accommodations (Bernheimer & Weisner, 2007) to their family routines due to their children's sensory experiences. Accommodations found in this study included making different foods at

mealtimes, structuring the daily routines to help assuage reactions to negative sound experiences (e.g., brother's violin practice or the use of a food processor), as well as more extreme examples of accommodations, such as the decision to home school a child. The importance of family time and togetherness in everyday routines noted in this study are also supported by Evans and Rodger (2008) as well as Tubbs, et al. (2005). I was able to identify patterns of parental engagement as discussed by Primeau (2000), in the participants' descriptions of meaningful routines. For example, parents in this study often identified which parent performed particular parts of bathtime and bedtime routines.

Parents of both typically developing children and children with autism emphasized the importance of physical activity in family occupations. Fiese (2006) described how family routines can contribute to family health, which may also help to explain the importance of engagement in physical activity to the families in this study. Alternatively, Umstatt, Wilcox, Saunders, Watkins and Dowda (2008) examined the relationship between self-regulation and physical activity in older adults. This relationship between physical activity and self-regulation could also help to explain the importance of physical activity to the families in this study. Many parents of both children with autism and typically developing children in this study either acknowledged or intimated that participation in physical activity had a type of self-regulatory effect in their children. The importance of "getting the energy out" is also supported by the findings of Kuo, et al.'s (2008) time use study of adolescents with autism, which identified the importance of physical activity.

Both groups of parents identified ways in which their children's sensory experiences affected their families' social participation. Social participation was an aspect of family occupations that differed considerably between families of typically developing children and children with autism. The parents of children with autism tended to limit or avoid particular places or situations due to their children's sensitivity to sensory experiences, while the parents of typically developing children commonly emphasized the opportunities that opened to the family because of children's enjoyment of sensory experiences. In essence, it seemed difficult for the parents of children with autism to achieve a good 'fit' (Law, et al., 1996) in their family occupations.



Parents of typically developing children often wanted their children to be exposed to negative sensory experiences in order to develop independent problem-solving skills and coping mechanisms. Parents of children with autism, on the other hand, frequently mentioned avoidance of certain sensory environments. The effects on social participation and avoidance of certain sensory experiences, noted namely by parents of children with autism in this study, reflect existing literature. These findings confirm the differences in sensory processing in children with autism as illustrated by Baranek, et al. (2008) and Watling, et al. (2001). Existing literature also notes potential ramifications for the children related to the families' participation in social and leisure occupations. Long-term implications of families' avoidance of or participation in activities have been noted by King, et al. (2006) and Orsmond, et al. (2004). These studies proposed that family participation in social and recreational activities was a factor in determining children's participation in activities. Family participation essentially sets the stage for children's participation. That is, if families choose to avoid certain situations or activities, the children learn to do the same. Alternatively, if families choose to participate in social and recreational activities, the children learn to participate as well.

Additionally, King, et al. (2006) noted that if parents perceive an environment to be unsupportive, their child's participation in activities is negatively affected. This appeared to be true for the parents of children with autism and a few of the younger typically developing participants in this study. In short, families did not go to places or participate in activities where they did not feel welcome. Kuo, et al. (2008) noted that adolescents with autism spent more discretionary time with family members than with peers. The contextual descriptions of occupations provided by the parents of children with autism in this study also confirms Kuo, et al.'s finding. Parents of children with autism made very few references to occupations performed with peers; rather, these parents usually described occupations performed with family members. However, it should be noted that parents' descriptions of their children's occupations may have been influenced by the family-centered nature of this study.

Parents of both typically developing children and children with autism described increased planning and preparation for occupations with strong sensory components, yet the number and extent of alternate plans in the parents of children with autism was striking. Parents of children in both groups in this study noted that increased planning was involved in meal preparation, outdoor activities, and sporting events. This finding is confirmed by the importance of planning and prioritizing noted by Evans and Rodger (2008) that occurs within families in order to maintain routines. Yet breadth and depth of alternate plans mentioned by parents of children with autism confirmed the need for predictability, organization, and adaptations noted by Larson (2006) in her study of mothers of children with autism. This study also reflected the everyday challenges inherent in living with a child with autism noted by DeGrace (2004). However, through the use of a comparison group, I was able to emphasize overlapping effects of children's sensory experience on family occupations in both groups. This comparative technique enabled me to provide a somewhat more optimistic view of family occupations in children with autism as compared to existing literature. For example, while DeGrace found the families of children with autism in her study had only short-lived moments of feeling like a family, this study demonstrated the significance of family time and the importance of creating memories through sensory-laden family occupations.

The final way in which children's sensory experiences affect family occupations was the extent to which experiences, meaning, and feelings are shared. Although feelings were generated based on family occupations for participants in both groups, the exchange of thoughts and feelings usually occurred in the families of typically developing children and occasionally in older children with autism. Hasselkus (1998) used the term 'meeting of minds' to describe the connection and understanding that must exist in order to create mutual engagement in an occupation. This meeting of the minds appeared to be lacking, or was at least harder to achieve, for parents of children with autism. Perhaps a study by Woodgate, Ateah, and Secco (2008) can help to explain this difficulty in achieving a meeting of the minds. Woodgate, et al. described the isolation experienced by parents of children with autism because the parents felt "like they were not a part of the world that their child

with autism lived in” (p. 1078). The inability to feel as if one is living in the same world as one’s child could certainly help to explain the challenges in sharing experiences, meaning, and feelings related to a family occupation.

The pervasive feelings of confusion, incompetency, and worry experienced by parents of children with autism in this study were mitigated by parents’ ‘search for the key’ (Hasselkus, 1998) to shared experiences. Parents of children with autism described ways in which they searched for a vehicle to better understand their children, such as through books, conferences, special diets, and the use of therapists. This drive to get “educated,” as one parent called it, was also noted by Woodgate, et al. (2008). In Woodgate, et al.’s study parents of children with autism described the need to “learn all you can” and “educate others” (p. 1081). This sentiment was echoed by the parents of children with autism who participated in this study.

Perhaps Spitzer’s (2003) definition of occupation for children with autism could help parents reframe their definitions of meaningful activities. Spitzer proposed that occupations can be defined as directed actions that need only be meaningful to the individual executing them. Understanding occupations from the child’s perspective could facilitate parents’ efforts to find the key and create a meeting of the minds. Adam and Anna provided excellent examples of understanding occupations from their children’s perspectives. Adam described how his family played together in the rain due to his son’s love of water. Anna described the pleasure she and her family derived from outdoor activities related to the self-regulatory effects of physical activities for her son. More families could benefit by following the examples set by Adam and Anna and embedding positive sensory experiences for their children within meaningful family occupations.

Although I noted challenges related to family occupations in parents of children with autism, the short-lived feelings of family and the lack of happiness and satisfaction discussed by DeGrace (2004) were not as evident in my findings. In fact, parents often commented on conscious decisions not to avoid participation in particular occupations simply because of a diagnosis of autism. And although the sharing of experiences, meaning, and feelings during family occupations was not as

extensive as the exchange noted by parents of typically developing children, there was still a sense of meaning and togetherness derived from family occupations in the parents of children with autism.

The notion of ‘performance range’ as discussed by Dunn, et al. (1994) in their proposal of the EHP theory helps to frame the findings. Children’s sensory experiences, the extent of preparation and alternate plans, as well as the amount of shared meaning, feelings, and experiences affect the performance of family occupations. It is important to note that since families are open systems (Humphry & Case-Smith, 2005), this is a dynamic model. Baranek, et al. (2001) has already provided a model to demonstrate the dynamic nature of sensory processing. The model provided here builds on the existing literature regarding dynamic systems interacting in families (Humphry & Case-Smith) as well as the dynamic nature of sensory processing (Baranek, et al.).

Figure 1 represents how a typically developing child’s sensory experiences might affect family occupations. The bi-directional arrows in Figure 1 indicate the dynamic effects of: (a) children’s sensory experiences; (b) the extent of preparation and alternate plans required; and (c) the lack of shared meaning, feelings, and experiences on family occupations. In the family of a typically developing child, the child’s sensory experiences lead to increased performance range of family occupations. The size of the ‘Family Occupations’ circle signifies that the family chooses to participate in many occupations and does not choose to avoid many occupations. More experiences, meaning, and feelings are shared in family occupations. A relatively small number of alternate plans and advanced preparation is needed. The advanced preparation leads to enhanced performance of family occupations.

Figure 1. Effects of typically developing children's sensory experiences on family occupations

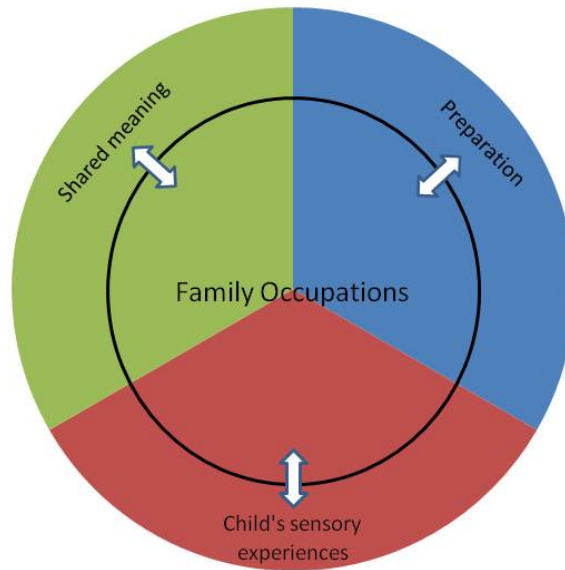


Figure 2 represents how sensory experiences of children with autism affect family occupations. In the family of a child with autism, the child's negative or unusual responses to sensory experiences lead to decreased performance range of family occupations. The decreased size of the 'Family Occupations' circle signifies that the family chooses to participate in fewer occupations and chooses to avoid some occupations. The small amount of shared experiences, meaning, and feelings related to family occupations also decreases the performance range. In other words, when parents have to 'search for the key' to achieve 'a meeting of the minds,' the performance range of family occupations decreases. In families of children with autism a greater number of alternate plans and advanced preparation is needed. Despite much advanced preparation, the performance of family occupations is often negatively affected.

Figure 2. Effects of children with autism's sensory experiences on family occupations

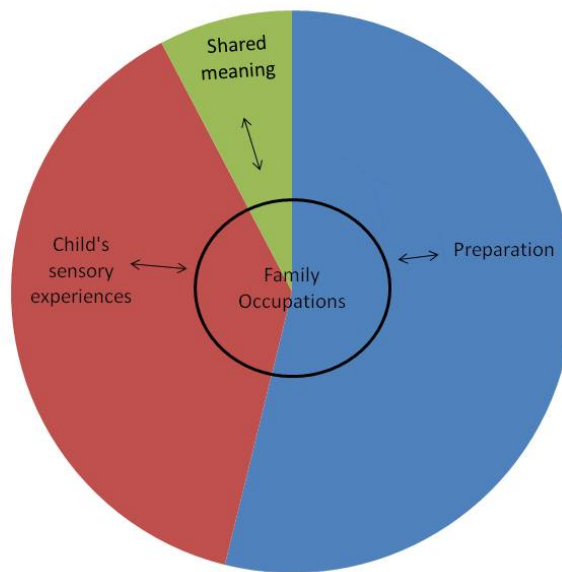
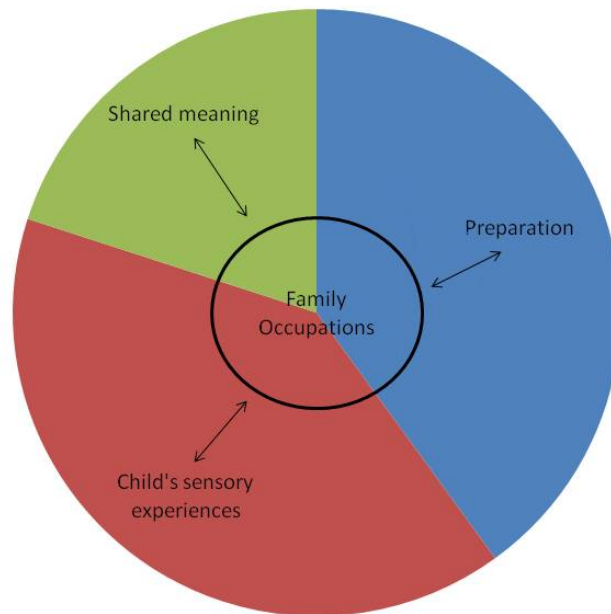


Figure 3 shows the effects of a child's sensory experiences on family occupations for a typically developing child who is having a bad day. It serves to emphasize the overlapping areas between typically developing children and children with autism. If a typically developing child is having a bad day, the child's sensory experiences might be more irritating to him or her and thereby impinge upon family occupations. If the parent realizes the child is having a bad day, he or she might bring along more toys or devise more exit strategies in preparation for the child's response to the occupation, thereby constricting the family's performance range. Additionally, if the parent becomes agitated with the child's negative behavior, a decrease in shared meaning, feelings, and experiences during a family occupation could result.

Figure 3. Effects of a typically developing child’s sensory experiences on family occupations when the child is having a bad day



### *Clinical Implications*

The role of therapists was clearly evident in parents’ descriptions of their children’s sensory experiences and family occupations in the autism group. According to these parents, occupational therapists appeared to be most helpful when they coached families and facilitated interpretation of their children’s behaviors and responses. I was also struck by the long-lasting effects of therapists’ recommendations. Four of the six parents of children with autism in this study cited specific examples of family occupations that had been modified or established to include recommendations from occupational therapy practitioners. For example, Anna talked about how her understanding of her son’s sensory needs, as explained by her occupational therapist, led the family to hike regularly. Amanda described how she made it a point for the family to eat dinner together because years ago a therapist had educated her on the “closeness” created as well as the implied messages and lessons conveyed during family mealtimes. Amy described how she learned to build her son’s coping skills in

a non-verbal way by scaffolding his sensory experiences. She described how she responded when her son vomited after she put a large ball of Play-doh in his hand. She said, “I probably would have not reintroduced it. But [the therapists] said... you got to keep reintroducing it, because...he might not be able to have the *big, giant* ball in his hand, but he can have a little bit.” Other parents mentioned regular outdoor play on the playground or therapeutic riding occupations that resulted from therapists’ suggestions.

The parents of children with autism also used a significant amount of clinical jargon, much like that used by the parents in the study conducted by Dickie, et al. (2009). Parents regularly used phrases such as deep pressure, pressure into joints, self-direction, stimuli, sensory diets, vestibular input, sensory input, physical input, hyper, hypo, visual processing difficulties, and sensory seeking behaviors. The use of jargon could be gained through the aforementioned ‘search for the key’ (Hasselkus, 1998) and education. Alternatively, the use of jargon could be a byproduct of the fact that therapy has become such a significant part of these families’ routines. While the parents’ appropriate use of such clinical terms is impressive and possibly helpful when speaking to clinicians and serving as advocates for their children, there is a risk in parental usage of jargon. It is possible that parents could further pathologize their children, which could derail the search for shared experiences and feelings during family occupations.

It is important that occupational therapy practitioners take a transactional view of family occupations. Occupations are a prime example of significant transactions in everyday life. Dickie, Cutchin, and Humphry (2006) stated, “Occupation can be viewed as a transaction joining person and situation.” Occupations are transactions that provide meaning and outcomes for people of all ages. In a transaction, all things are interpenetrating, because as these authors suggested, the things in a transaction “should be considered co-defining and co-constitutive” (p. 88). A person cannot be seen apart from his/her context (Dickie, et al.). When OTs take a transactional perspective with regard to sensory experiences and family occupations, they are better able to offer strategies to manage the situation, rather than attempting to solely change the child. Yet through this transactional perspective,



it is necessary to recognize that the strategies offered to manage the situation will inherently affect the child, as all elements of a transaction affect one another.

A transactional view (Dickie, et al., 2006) of sensory experiences and family occupations could also facilitate shared meaning among family members. During the interviews I conducted for this study, I noted how difficult it was for parents of typically developing children to identify sensory experiences as compared to the parents of children with autism. At the end of Tara's interview she explained how difficult it was for her to provide examples of her son's sensory experiences. She stated, "It's just not something you think about all the time." The parents of children with autism, however, seemed to be far more aware of sensory components inherent in certain occupations and environments. Because parents of children with autism were so focused on the sensory components, they seemed to have a different perspective than the parents of typically developing children. Focusing on component pieces of the environment could obscure the broader meaning of the family occupation, while focusing on the transaction emphasizes shared meaning and experiences.

Another implication for occupational therapy practitioners that resulted from this study was the fact that meaningful occupations can "trump," as one parent called it, uncomfortable sensory experiences. This was true for children in both the typically developing group as well as the autism group. Sometimes the meaning attached to an occupation helped a child tolerate an uncomfortable sensory experience. For example, Anita described how her son enjoyed swimming outside, despite the multitude of sensory experiences embedded in the occupation, because swimming was the one occupation the boy regularly did with his father. Tiffany described how much her son enjoyed building activities in the sandbox, despite his dislike of messy activities. The boy's "love for building and creating" trumped the messiness associated with play in a sandbox.

In another example, Anna described how her son often had negative sensory experiences related to sound, yet loved riding roller coasters. She stated, "The emotional meaning will trump the sensory problem. You know, like roller coasters... he loves going on roller coasters. And what's louder than that?" It is possible that the emotional significance connected to riding a roller coaster in a

meaningful context helped the child to deal with the loud noises. Alternatively, it could be that the movement the boy experienced on the roller coaster trumped the loud noise. It was interesting to note that a single occupation could encompass both good and bad sensory experiences.

Prior to this study, I underestimated the amount of planning and preparation that families performed in order to facilitate or sustain participation in family routines and occupations. I now recognize that this is an area where occupational therapists might assist in offering strategies to help families manage sensory-laden occupations. Additionally, this study helped me to appreciate that many routines possess, or have the potential to possess, positive sensory experiences. This is another area where occupational therapists might facilitate a meeting of the minds. Playing in the rain together or enjoying a family hike could help create a shared experience and might lead to a meaningful family occupation.

### *Limitations*

There were some limitations to this study that I wish to note. First, the families of typically developing children were recruited through convenience sampling. Ideally, in a grounded theory study theoretical sampling should be employed (Strauss & Corbin, 1990). It was also difficult to obtain a homogeneous group (Creswell, 2007) of children with autism due to the wide range of the symptoms and behaviors that are included on the autism spectrum. Although the families in this study were sampled based on convenience, the two groups to which my participants belonged provided what Strauss and Corbin called “proven theoretical relevance” (p. 176). In other words, concepts were noticeably present or absent within and between the groups (Strauss & Corbin). The existence of proven theoretical relevance lends credence to the nature of sampling employed in this study.

Second, parents of typically developing children were screened using a form developed for the larger study and interviewed using the PEDS Response Form (Glascoe, 2000), rather than verifying typical development through the use of a norm- or criterion-referenced assessment. Third, only one interview was conducted with each family. Interviews ranged from approximately 20 to 70

minutes. Additionally, interviews were mainly conducted with mothers, rather than with fathers, with both parents, or with the children themselves. Fourth, due to the geographic location of the study, more highly educated parents were sampled. Finally, only one family in the autism group and two mothers in the typically developing group were not Caucasian; thus a more ethnically diverse sample would have been beneficial.

Despite these limitations, this study captured rich and insightful glimpses into the lives of families. Regardless of the length of the interviews, the geographic location of the study, or the gender of the parents interviewed, this study fills a gap in existing OT literature. It examines how family occupations are affected by children's sensory experiences. Although much research has been conducted on sensory processing and responses in children, until this study, the effects of these experiences on the family occupations and routines had not been explored in detail. This study demonstrates that a child's sensory experiences affect family occupations, regardless of whether the child has a diagnosis. Additionally, my use of a comparison between families of children with autism and families of typically developing children provides a different, and potentially more optimistic, view of everyday life with a child with autism.

### *Future Directions*

The comparison groups used in this study provided a different perspective from most existing literature on families of children with autism. More qualitative studies that employ a comparison group could help to elicit data that emphasizes specifically how family life in children with special needs is similar to or different from families of typically developing children. Although this study tends to highlight parents and children, throughout the course of the interviews I noticed effects of children's sensory experiences on siblings' occupations. The effect of children's sensory experiences on siblings and their occupations is an area for potential future research, especially if we consider a family-centered approach to treatment. The notion of shared meaning and experiences during family

occupations is another topic that would benefit both occupational science as well as occupational therapy. The more occupational scientists understand about how people derive meaning from occupations, the more occupation therapists will be able to employ strategies to foster shared meaning in practice.

## Chapter 6: Conclusion

Based on the results of this qualitative study, I have developed a grounded theory to explain how children's sensory experiences affect family occupations. Children's sensory experiences affect: (a) what the family chooses to do or not; (b) how the family prepares; and (c) the extent to which experiences, meaning, and feelings are shared during a family occupation. The power of everyday family routines, especially bedtime, bathtime, and mealtime, was evident in both groups. Parents in both groups noted self-regulatory effects of physical activity. The effects of children's sensory experiences had on social participation differed between the families of children with autism and the families of typically developing children. Parents of typically developing children noted that their children's enjoyment of sensory experiences created more opportunities for the family, whereas the parents of children with autism noted some limitations on social participation in the community. Families of children with autism mentioned more avoidance of certain sensory experiences, while parents of typically developing children described how they purposely exposed their children to stimulating sensory environments in hopes of developing problem-solving and coping skills.

Parents of both typically developing children and children with autism described increased planning and preparation for occupations with strong sensory components, yet the number and extent of alternate plans in the parents of children with autism was noteworthy. Feelings were generated based on family occupations for participants in both groups; however the exchange of thoughts and feelings usually occurred in the families of typically developing children and occasionally in older children with autism. Parents of children with autism seemed to be 'searching for the key' (Hasselkus, 1998) to create a meeting of the minds that would enable mutual engagement in family occupations.

## Appendix: Interview Script

The following is a copy of the interview script I used with participants:

1. Tell me about a recent time when your child felt especially good because of a sensory experience he/she was having?
  - a. Prompt 1: It could be something he/she was feeling, touching, smelling, hearing, and/or tasting. Or it could be movement.
2. How did you discover it's something your child enjoys?
  - a. Probe for context: When did it happen? What else was going on? Who was there?  
Where were you?
3. What's your sense of what it's like for your child when he/she is \_\_\_\_\_?
4. What's it like for you as a parent when your child is feeling especially good about a sensory experience?
5. Tell me about a recent time when your child felt especially bad because of a sensory experience he/she was having?
  - a. Prompt 1: It could be something he/she was feeling, touching, smelling, hearing, and/or tasting. Or it could be movement
6. How did you discover it's something the child dislikes?
  - a. Probe for context: When did it happen? What else was going on? Who was there?  
Where were you?
7. What's your sense of what it's like for your child when he/she is \_\_\_\_\_?
8. What's it like for you as a parent when your child's feeling especially bad about a sensory experience?
9. Can you describe a time when your child seemed to respond strongly to sensory things?
  - a. Prompt 1: My friend can't stand the sound of a tea kettle whistling and will run to the kitchen to stop it;

- b. Prompt 2: Perfume really bothers me
  - c. Probe for context: When did it happen? What else was going on? Who was there?  
Where were you?
10. Can you describe a time when your child didn't seem to respond to sensory things?
- a. Prompt 1: Last night I didn't even hear the phone ring.
  - b. Prompt 2: I used spoiled milk last week in my coffee and didn't even realize it was bad.
  - c. Probe for context: When did it happen? What else was going on? Who was there?  
Where were you?
11. Can you describe a time when your child really seemed to go out of his/her way to have a sensory experience?
- a. Prompt 1: I always have to touch fabric at stores.
  - b. Prompt 2: I love spicy food and always add hot sauce to things. I love warm baths. I always drag my hand along the water when I'm in a boat. I always run my fingers through the sand at the beach.
  - c. Probe for context: When did it happen? What else was going on? Who was there?  
Where were you?
12. Can you describe a time when your child seemed especially aware of, but not bothered by, sensory things that other people didn't notice?
- a. Prompt 1: I heard a dog barking the other night, but my husband/friend didn't hear it.
  - b. Prompt 2: I heard a humming sound from my office light yesterday. Or, I smelled a gas leak before my husband/friend did.
  - c. Probe for context: When did it happen? What else was going on? Who was there?  
Where were you? Where were you?
13. Could you tell me about some routine events that happen in your family?

- a. Prompt 1: Routine events could include meal time, bedtime, bathtime, and/or birthdays/holidays. What are these events like in your family?
  - a. Probe for context: When did it happen? What else was going on? Who was there?  
Where were you?
14. What meaning do these events have for your family?
15. How are the things you do as a family affected by your child's sensory experiences?
- a. Prompt 1: Anything you do more? Less? Differently?
  - b. Prompt 2: daily routine, relationships, community
16. How have your child's sensory experiences changed the way you experience the world?
- a. Prompt 1: One of the researchers noticed that since her children liked trucks and construction equipment, she would notice it even when her kids were not around.



## References

- American Occupational Therapy Association. (2008). Occupational therapy practice framework: Domain and process (2<sup>nd</sup> ed.). *American Journal of Occupational Therapy*, 62, 625-683.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4<sup>th</sup> ed.). Washington, DC: Author.
- Baranek, G.T., Reinharsten, D., & Wannamaker, S. (2001). Play: Engaging children with autism. In R. Heubner (Ed.), *Sensorimotor interventions in autism*. (pp. 311-351). Philadelphia: F.A. Davis.
- Baranek, G.T., David, F.J., Poe, M.D., Stone, W.L., & Watson, L.R. (2006). The sensory experiences questionnaire: Discriminating response patterns in young children with autism, developmental delays, and typical development. *Journal of Child Psychology and Psychiatry*, 47, 591-601.
- Baranek, G.T., Boyd, B., Poe, M., David, F., & Watson, L. (2007). Hyperresponsive sensory patterns in young children with autism, developmental delay, and typical development. *American Journal on Mental Retardation*, 112(4), 233-245.
- Baranek, G.T., Wakeford, L., & David, F. (2008). Understanding, assessing, and treating sensory-motor issues. In K. Chawarska, A. Klin, and F. Volkmar (Eds.), *Autism spectrum disorders in infants and toddlers: Diagnosis, assessment and treatment* (pp.104-140). New York: The Guilford Press.
- Bernheimer, L. & Weisner, T. (2007). "Let me just tell you what I do all day...": The family story at the center of intervention research and practice. *Infants and Young Children*, 20, 192-201.
- Centers for Disease Control and Prevention. (2008, January 30). *Autism spectrum disorders overview*. Retrieved October 3, 2008, from <http://www.cdc.gov/ncbddd/autism/overview.htm>
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: Sage Publications.
- Creswell, J.W. (2007). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage Publications.
- Crowe, T. (2002). Consistency of family routines over time in families with children with disabilities. *Occupational Therapy Journal of Research*, 22S, 92S-93S.
- Dalrymple, N. J. & Ruble, L. A. (1992). Toilet training and behaviors of people with autism: Parent views. *Journal of Autism and Developmental Disorders*, 22, 265-275.
- DeGrace, B.W. (2004). The everyday occupation of families with children with autism. *American Journal of Occupational Therapy*, 58, 543-550.

- Dickie, V. A., Baranek, G. T., Schultz, B., Watson, L. R., & McComish, C. S. (2009). Parent reports of sensory experiences of preschool children with and without autism: A qualitative study. *American Journal of Occupational Therapy, 63*, 172–181.
- Dickie, V., Cutchin, M., & Humphry, R. (2006). Occupation as transactional experience: A critique of individualism in occupational science. *Journal of Occupational Science, 13*, 83-93.
- Dunn, W., Brown, C., & McGuigan, A. (1994). The ecology of human performance: A framework for considering the effect of context. *American Journal of Occupational Therapy, 48*, 595 – 607.
- Dunn, W. (1997). The impact of sensory processing abilities on the daily lives of young children and their families: A conceptual model. *Infants and Young Children, 9*(4), 23-35.
- Evans, J. & Rodger, S. (2008). Mealtimes and bedtimes: Windows to family routines and rituals. *Journal of Occupational Science, 15*(2), 98-104.
- Fiese, B. (2006). *Family routines and rituals*. New Haven, CT: Yale University Press.
- Fiese, B. (2007). Routines and rituals: Opportunities for participation in family health. *Occupational Therapy Journal of Research, 27S*, 41S-49S.
- Flanagan, J. (1954). The critical incident technique. *Psychological Bulletin, 51*, 327-358.
- Francis-Connolly, E. (2002). The unpredictability of habits and routines for mothers of preschool-age children. *Occupational Therapy Journal of Research, 22S*, 94S-95S.
- Gallimore, R. & Lopez, E.M. (2002). Everyday routines, human agency and ecocultural context: Construction and maintenance of individual habits. *Occupational Therapy Journal of Research, 22S*, 70S-77S.
- Glascoe, F.P. (2000). *PEDS Response Form*. Nashville, TN: Ellsworth and Vandermeer Press.
- Gray, D. E. (2006). Coping over time: the parents of children with autism. *Journal of Intellectual Disability Research, 50*, 970-976.
- Harkness, S., Super, C., Sutherland, M., Blom, M., Moscardino, U., Mavridis, C., & Axia, G. (2007). Culture and the construction of habits in daily life: Implications for the successful development of children with disabilities. *Occupational Therapy Journal of Research, 27S*, 33S-40S.
- Hasselkus, B. (1998). Occupation and well-being in dementia: The experience of day-care staff. *American Journal of Occupational Therapy, 52*, 423-434.
- Hasselkus, B. & Dickie, V. (1994). Doing occupational therapy: Dimensions of satisfaction and dissatisfaction. *American Journal of Occupational Therapy, 48*, 145-54.
- Higgins, D., Bailey, S., & Pearce, J. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism, 9*(2), 125-137.
- Humphry, R. & Case-Smith, J. (2005). Working with families. In J. Case-Smith (Ed.), *Occupational therapy for children* (6<sup>th</sup> ed.) (pp. 117-153). St. Louis, MO: Mosby, Inc.

- Kellegrew, D.H. (2000). Constructing daily routines: A qualitative examination of mothers with young children with disabilities. *American Journal of Occupational Therapy*, 54, 252-259.
- King, G., Law, M., Hanna, S., King, S., Hurley, P., Rosenbaum, P., Kertoy, M., & Petrenchik, T. (2006). Predictors of the leisure and recreation participation of children with physical disabilities: A structural equation modeling analysis. *Children's Healthcare*, 35, 209-234.
- Koegel, R. L., Schriebman, L., Loos, L. M., Dirlich-Wilhelm, H., Dunlap, G., Robbins, F. R., & Plienis, A. (1992). Consistent stress profiles in mothers of children with autism. *Journal of Autism and Developmental Disorders*, 22, 205-216.
- Kuo, H. Orsmond, G., & Seltzer, M. (2008, April). *Time use of adolescents with autism spectrum disorders*. Poster session presented at the annual meeting of the American Occupational Therapy Association, Long Beach, CA.
- Larson, E. (2006). Caregiving and autism: How does children's propensity for routinization influence participation in family activities? *Occupational Therapy Journal of Research*, 26(2), 69-79.
- Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The person-environment-occupation model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63, 9-23.
- Lord, C., Rutter, M., Dilavore, P., & Risi, S. (1999). *The Autism Diagnostic Observation Schedule (ADOS)*. Los Angeles: Western Psychological Corporation.
- Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism Diagnostic Interview-Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 24, 659-685.
- Muhr, T. (2004). Atlas.ti (Version 5.0) [Computer software]. Berlin, Germany: ATLAS.ti Scientific Software Development GmbH.
- National Institute of Child Health and Human Development. (2008, August 6). *Autism spectrum disorders*. Retrieved May 15, 2009 from <http://www.nichd.nih.gov/health/topics/asd.cfm>
- Orsmond, G., Krauss, M., & Seltzer, M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disabilities*, 34, 245-256.
- Primeau, L. (2000). Divisions of household work, routines, and child care occupations in families. *Journal of Occupational Science*, 7(1), 19-28.
- Rodrigue, J., Morgan, S., & Geffken, G. (1990). Families of autistic children: Psychological functioning of mothers. *Journal of Clinical Child Psychology*, 19, 371-379.
- Rogers, S. (2005). Common conditions that influence children's participation. In J. Case-Smith (Ed.), *Occupational therapy for children* (6<sup>th</sup> ed.) (pp. 160-215). St. Louis, MO: Mosby, Inc.
- Schwandt, T. (2007). *The Sage dictionary of qualitative inquiry* (3<sup>rd</sup> ed.). Thousand Oaks, CA: Sage Publications.

- Segal, R. (1999). Doing for others: Occupations within families with children who have special needs. *Journal of Occupational Science*, 6(2), 1-8.
- Segal, R. (2004). Family routines and rituals: A context for occupational therapy interventions. *American Journal of Occupational Therapy*, 58, 499-508.
- Shangraw, K. (2007). Autism spectrum disorders. In B. Atchison and D. Dirette (Eds.), *Conditions in occupational therapy* (3<sup>rd</sup> ed.) (pp. 23-49). Philadelphia: Lippincott Williams and Wilkins.
- Spitzer, S. (2003). With and without words: Exploring occupation in relation to young children with autism. *Journal of Occupational Science*, 10, 67-79.
- Strauss, A. & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage Publications.
- Tubbs, C.Y., Roy, K., & Burton, L.M. (2005). Family ties: Constructing family time in low-income families. *Family Process*, 44(1), 77-91.
- Tunali, B. & Power, T. G. (2002). Coping by redefinition: Cognitive appraisals in mothers of children with autism and children without autism. *Journal of Autism and Developmental Disorders*, 32, 25-34.
- Umstattd, M.R., Wilcox, S., Saunders, R., Watkins, K. & Dowda, M. (2008). Self-regulation and physical activity: The relationship in older adults. *American Journal of Health Behavior*, 32, 115-124.
- Watling, R.L., Deitz, J., & White, O. (2001). Comparison of sensory profile scores of young children with and without autism spectrum disorders. *American Journal of Occupational Therapy*, 55, 416-423.
- Woodgate, R., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research*, 18, 1075-1083.