Family Experiences of Mealtime Behaviors of Children with ASD

Thesis

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Abstract

**Objective:** Resistant eating behaviors in children with ASD are a significant stress factor that affects not only the parents but the entire family. The objective of this study was to enhance our understanding of the experiences these families go through on a daily basis. **Method:** Seven families with a child of a self-reported diagnosis of ASD, 4-8 years of age, and who met the criteria for resistant eating participated in the study. Each completed the Sensory Profile and a three-day food journal. The researcher interviewed each mother and observed the child eating a meal/snack. The open ended interviews with probes were recorded and transcribed verbatim. A follow-up phone call was used to verify critical issues to determine if the parents agreed with the interpretations. The transcripts were then used to obtain common themes among the families and their children. **Results:** Four themes emerged from the analysis of the transcripts of the interviews and field notes of the observations. The first theme was ritualistic, rigid behaviors seem to be key to resistant eating behaviors. All the children had at least one rigid routine, if not more than one that when these routines were not followed inappropriate mealtime behaviors would ensue. Another theme was compromises. The parents made compromises or devised strategies to assure that nutrients are consumed. The most common compromise was multiple meal preparations. The third theme that emerged was how these families manage social situations. All these families indicated that the behaviors have impacted the family’s social life. Taking a trip to a restaurant or family gathering required careful planning and may be disrupted at any point due to the child’s mealtime behaviors. The final theme that emerged was the family stress. Many mothers indicated that coping with their children’s eating behaviors was stressful to the entire family. The mothers felt guilty and took the blame for their children’s nutrition and eating behaviors. They also felt guilty about the impact it has on the siblings. **Conclusions:** Using the mothers’ perspectives, this study provided insight into the family life of ASD children with resistant eating behaviors and identified common themes on how resistant eating and ritualistic behaviors affect family life.
Dedication

This thesis is dedicated to my loving and supportive family. To my loving husband, Greg, who always encouraged and supported me and my dream of attained my Master’s degree. I only wish he were still alive today to see this dream become a reality. To my wonderful and supportive children, Joshua, Stacy and Brittany and my daughter-in-law, Shandra who took time out of their own busy schedules and studying to read through and edit papers, transcribe interviews, cook, clean and help me maintain my sanity. To my sweet little grandson, Riley who always provided the much needed distraction and necessary break in my work. I would like to thank my parents, Clair and Joann Rehm who have encouraged and supported me through all the years of hard work. Thank you for without all of your help, this dream would never have become a reality.
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I want to thank my family for their patience and support. Without you, all this hard work would be for nothing.

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Fields of Study

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Chapter 1

Introduction

Autism, or autism spectrum disorder (ASD), has increased in its incidence rate in the past several years. Autism Speaks reports that 1 out of 150 children are diagnosed with some form of Autism. It occurs in all racial, ethnic and socioeconomic groups and can range from very mild to severe. Boys are four times more likely than girls to have ASD (National Education Association, 2006; William, Kendell-Scott, & Costall, 2005). ASD is under the diagnostic umbrella of Pervasive Developmental Disorders (PDD) according to the Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM-IV, 1994). ASD is a neurobiological condition that affects the social interactions and communication skills of the individual as well as the presence of unusual behavior or interests (Autism Speaks, 2007; Bowers, 2002; Lukens, 2005; National Education Association, 2006). Also associated with ASD are the rigid routines and repetitive behaviors, as well as the child’s ability to regulate and process sensory information. A reliable diagnosis can be made by the time the child is three years of age but children have been diagnosed as young as six months of age (Autism Speaks 2007). Children with ASD tend to have similar characteristic behaviors that uniquely affect each individual, however, because of the combination of the varying degrees of severity as well as their behaviors and rituals, ASD manifest differently in each child.

As mentioned above, children with ASD do not regulate and process sensory information in a typical manner. Sensory processing disorders can affect behaviors (e.g., responses to the environment), social interactions, and may specifically affect eating. These children may be considered picky eaters because they restrict or limit certain foods, food groups or textures from their diet. Children who only eat fifteen foods or less are considered resistant eaters (Ernsperger & Stegen-Hanson, 2004). Chatoor & Ganiban, 2003; Ferreri, Tamm, & Wier, 2006; Timimi, Douglas & Tsiftsopoulou, 1997; Williams et al., 2005 indicated that as many as 25% of the toddlers and preschoolers that are developing typically are considered picky eaters at this age; however this is considered a transient problem. Of the special needs toddlers and preschoolers, as many as 13 to 80% can have some transient problems with limited food selections (Ahearn,
however, children who do not “grow out of it” are considered to have a chronic form of resistant eating. Children diagnosed with ASD are frequently among the children who chronically limit their diet to completely avoid or eliminate certain food groups and/or textures, refuse to try new foods, or have ritualistic behaviors/patterns. They often have highly specific preferences for the way their food is prepared, colors of foods (i.e. all yellow foods) and/or presentation such as a specific cup/plate. It is believed that if the condition lasts longer than two years, it is considered chronic and if the problem is not addressed, these behaviors are likely to continue and long term exposure to resistant eating may increase the risk for medical and nutrition-related problems. (Kern & Marder1996; Nicholls, Christie, Randall, & Lask, 2001; Williams, Dalymple, &Neal, 2000)

Some studies (Ahearn et al., 2001; Crist & Napier-Phillips, 2001; Lukens, 2005; Nicholls et al., 2001; Schreck and Williams 2006; Timimi et al., 1997; Whiteley, Rodgers, & Shattock, 2000; Williams et al., 2000) have found that ASD children tend to eat more sweets and carbohydrates than other children, resulting in taste buds that do not experience the sweet taste and therefore, crave more sweets. The child becomes a ‘super taster’, a physiological reaction causing the tongue to have an extreme sensitivity to bitter taste. These children also drink excessive amounts of liquids, lending to their poor eating behaviors

These feeding problems are a result of several factors that probably interact with each other. (Ahearn et al., 2001, Crist & Napier-Phillips, 2001; Ferreri et al., 2006; Field, Garland, & Williams, 2003; Luken, 2005; Whiteley et al., 2000; William et al., 2005) The three factors identified are biological, behavioral and social. Biological factors include structural abnormalities such as a cleft palate, neurological conditions, cardio-respiratory problems, metabolic conditions and unusual sensory processing skills (Chatoo & Ganiban, 2003; Luken, 2005; William et al., 2005). Behavioral issues were closely tied to psychosocial difficulties that included dysfunctional interactions between the child and caregiver, emotional difficulties and negative feeding behaviors that were maintained by internal and external reinforcements.

Social issues were often seen as the child’s inability to eat with others and later lead to
social anxiety. Chatoor & Ganiban’s 2003 study suggested that these eating behaviors are a result of familial genetic traits. If the parents are resistant eaters, then the child would be offered less variety in food selections which could be considered the underlying reason the child is restrictive in his food choices.

According to Nicholls et al., (2001) and Timimi et al., (1997), the effect of resistant eating behaviors obviously impacts the family and can become a major family crisis as the child may be perceived as manipulative and the parents may feel resentment or doubt in their ability to parent. Chatoor & Ganiban, 2003; Crist &. Napier-Phillips, 2001; Williams et al., 2005; William et al., 2000 found that parental strategies such as making multiple meals were a frequent course of action for these caregivers. The parents are so concerned with the child’s lack of nutritional intake that they provide the child with a meal of preferred foods to ensure that the child eats. Additional meals are also made to reduce the number of tantrums and other behaviors associated with mealtime. It was found that these behaviors can include whining, crying, gagging, resisting self-feeding, spitting food out, leaving the table or refusing to come to the table, pushing or throwing the food, inconsistent eating schedules or using idiosyncratic behaviors such as using the same utensil/plate/cup, not allowing the food to touch or requiring specific food preparation (Ahearns et al., 2001; Ferreri et al., 2006; Field et al., 2003; Lukens 2005; Schreck & Williams 2006; Schreck et al., 2004; Timimi et al., 1997). Other parent strategies may include coaxing, negotiation, and in rare instances threats and force feedings: (Crist & Napier-Phillips 2001; Williams et al., 2005; William et al 2000). Negotiations are another way that parents try to increase their child’s food repertoire. However, as the child reaches the age of eight and over these parents often have “given up hope of changing their child’s eating habits” (Timimi et al., 1997).

Significance of the problem:

Resistant eating in children with ASD is significant because these families have very few positive and successful strategies to help their child become more accepting of a variety of foods (Nicholls et al., 2001; Timimi et al., 1997) and to be less rigid in their mealtime behaviors/patterns (Chatoor & Ganiban, 2003; Crist & Napier-Phillips, 2001; Williams et al., 2005). Exploring the idiosyncratic mealtime behaviors to which these children cling, and gaining
a perspective regarding the influences of the child’s resistant eating on the family, may allow therapists to develop strategies and possibly identify new treatment techniques. When a child exhibits resistant eating patterns and rigid mealtime behaviors, how does the family cope with family outings, family celebrations with extended families and daily routines?

**Research Questions:**

1. What mealtime behaviors are perceived by the families of ASD children with resistant eaters?
2. What commonalities and idiosyncratic behaviors are observed by the families in their children at mealtime?
3. What are the experiences of families of children with ASD who have resistant eating behaviors?

**Research Approach**

A qualitative research approach was proposed using a semi-structured in-depth interview (Lysack 2006) with the seven parents of children between the ages four to eight diagnosed with ASD who eat no more than fifteen foods. Children who were on special diets, such as casein-free and gluten-free were excluded. This study used an in depth interview process of parents of these children as well as an observation of their ritualistic behaviors. The research questions attempted to enhance our understanding of the experiences these families go through on a daily basis and to identify any commonalities between them.

**Glossary**

**Resistant eaters** defined by Ernsperger & Stegen-Hanson (2004) are children that limit food selections to 15 foods or less, limit food groups and refuse one or more food groups. In addition, these children experience anxiety and/or tantrums when presented with new foods. They may gag or become ill when presented with new foods. These children may require that the food is prepared and presented in the same manner at every meal. Resistant eaters are diagnosed with a developmental delay such as ASD and may have a diagnosis of mental retardation and have exhibited these behaviors for at least two years.
Sensory food aversions are another name for resistant eaters. Chatoor & Ganiban (2003) chose this term to describe the subjects in the study because it was observed as a sensory processing disorder as the child demonstrated other sensory processing issues. The child limited the food based on their aversion to the smell, taste or texture of it.

GERD stands for gastro-esophageal reflux disease. Based on the link of WEBMD.com (10-22-2007) infant and children produce symptoms of GERD which include frequent vomiting, coughing, breathing difficulties and a failure to thrive.

Echolalia repetitive vocalizations of sounds or speech that the child may hear and replicate the sophisticated language but this sophisticated language can only be heard in those specific and repetitive phrases

Food jags are the child’s insistence to eat the same foods in the same manner for an extended time. This behavior is typical for preschoolers, however, the food may change over time.

Limitations:
Limitations of this study was the sample size. There were seven families interviewed from a generalized local area of central Ohio.
Autism and Autism Spectrum Disorder

ASD, autism spectrum disorder is a term that health professionals are now using to refer to those disorders under the “PDD umbrella.” Under this “umbrella” of Pervasive Developmental Disorder (PDD) are five distinct disorders that range in severity across the categories and within the disorder itself. According to the Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM-IV, 1994), under this PDD umbrella include: Autism Disorder, Asperger’s Syndrome, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), Rett’s Disease, and Childhood Disintegrative Disorder. These disorders range in severity from mild to severe and many times no two children present with the same characteristics or severity. The three main areas that are considered when making a diagnosis of ASD are communication, social and stereotypical behaviors. ASD has been on the rise in the past several years. The Center for Disease Control (2007) indicates that the rate of diagnosed cases is 1 out of a 150 children. Boys are four times more likely than girls to be diagnosed with ASD (Albon, 2005; Tankersley & Cowan, 2007; William et al., 2005).

In the area of communication, the child demonstrates qualitative differences in his or her communication skills that affect both the verbal and nonverbal skills. A child with ASD may have functional speech but may become lost in the nuances of the language. A child with ASD may exhibit a language delay, a loss of language, use only functional communication, have odd usage of the language or use echolalic speech. Echolalia is the repetitive vocalizations of sounds or speech that the child may hear and replicate the sophisticated language but this sophisticated language can only be heard in those specific and repetitive phrases. Usually a young child repeats songs and/or phrases from movies/shows that the child watches. The child’s nonverbal language skills are also different from typically developing children in that many times their expressions do not match the emotion as the child may laugh instead of cry when hurt. The child may avoid eye contact and may use gestures to get his needs met. Children with ASD do not understand the subtleties of body language and facial expressions and joint attention is not
Social development is impacted by the child’s lack of nonverbal language skills. Since they avoid eye contact and are unable to discern body language, they miss the subtle cues of social skills or pragmatics. They do not interact with another to get a need or want met. They lack an awareness of other’s feelings or emotions because of their poor social reciprocity. They usually lack spontaneous conversation, imitation skills and social play skills. They frequently are non-responsive to siblings and peers when they try to interact with them (Albon, 2005; National Education Association, 2006; Williams et al., 2005).

Another characteristic of ASD children is the development of idiosyncratic behaviors that are restrictive and/or repetitive. The idiosyncratic behaviors may also be displayed as stereotypic patterns, interests or activities. Sometimes a child lines up certain toys and becomes upset if they are moved from the line. The child may also become ritualistic in routines; for example, at meal time, the child needs to be served with the same plate, cup and utensils or the child may refuse to eat. These behaviors may be more subtle in that the child only eats a certain brand of food or only eats it when it has been prepared a certain way. Another aspect of this characteristic may be unusual interests. The child’s range of interests may be affected by his inability to imitate, imagine or a lack of interest in toys. They may also have repeated motor movements, peculiar reactions to sounds or movements, odd visual behaviors or tactilely inspect items and/or a preoccupation or perseverance for activities or interests (Albon, 2005; National Education Association, 2006; Tankersley & Cowan, 2007; Williams et al., 2005).

**Pickiness in Eating with Typically Developing Children**

Toddlers, the years between one and three, can be challenging when trying to assure that they ingest the necessary nutrients. For a toddler, food jags are typical. One day they may eat only vegetables and the next day they may only eat fruit. At this age, children will refuse to try new foods because they think they dislike it or because they are afraid. The key to getting a toddler to eat new foods is to present the food so that the child becomes familiar with it. For example, a parent may make it fun to eat, such as using fruits to make a face on the pancake, or
just presenting the food to them many times so that the child becomes familiar with it. As the child becomes familiar with it, the food is usually accepted (Ernsperger & Stegen-Hanson, 2004; Jacobi, Agras, Bryson, & Hammer, 2003; Lewinsohn, Denoma, Gau, Joiner Jr., Striegel-Moore, Bear, & Lamoureux, 2005; Skinner, Carruth, Bounds, & Ziegler, 2002).

In general, children who were viewed as picky eaters were described by their parents as having a significantly longer feeding time than their non-picky counterparts. Parents reported that children who were resistant eaters frequently had three of the following behaviors: those that do not eat enough, those that are often choosy about what they eat, those who usually eat slowly and those children not interested in food. (Jacobi et al. 2003)

Jacobi et al. (2003), described resistant eaters as consuming limited number of foods, unwilling to try new foods, avoidance of certain food groups and strong preferences for certain foods. Resistant eaters also have a lower dietary variety meaning that while most of the children ate a variety, of dairy, breads and grains, proteins and condiments, children who were resistant eaters eat a limited variety in their fruits, vegetables and sweets (Higgins, Bailey, & Pearce, 2005).

Infants who were breast-fed appear to be more accepting of new foods than those children who relied on formula for their nourishment. Jacobi et al. (2003) found that children who became resistant eaters exhibited a decreased number of sucks, thereby, demonstrating a decreased sucking pattern as early as the first few months of life. Other characteristics of resistant eaters are that boys tend to exhibit this trait more frequently than girls. Boys were also more apt to avoid foods in the vegetable group than girls or non-resistant eaters.

Many different factors can impact a child’s acceptance of new foods. Several studies indicated that the number of opportunities a child is given to try a new food; the more familiar that food is to the child. The child then more readily accepts new foods. Children who were resistant eaters also appear to be influenced by the examples set by family members. Another reason for resistant eating may be the temperament of the child. Learning experiences and rewards can also impact the child’s acceptance of the new foods. However, rewards can
negatively impact the child’s acceptance of the new food as well (Lewinsohn et al., 2005; Skinner et al., 2002).

Resistant eating has been identified under many different names by as many researchers. For example, Chatoor & Ganiban, (2003) refer to three types of food refusal. The first one is an unpredictable food refusal. This is identified by the extreme inconsistencies in the toddler’s food preferences as well as the daily caloric intake. This behavior of refusing foods may occur as early as 6 months but typically is observed between 9 and 18 months of age up to age three. This usually occurs when the child is transitioning from spoon feeding to self-feeding. Parental reports indicate as a young infant he or she was more interested in looking around than drinking and usually consumed small amounts of breast milk/formula. This eating pattern resulted in frequent feedings. If these resistant eating behaviors become chronic, lasting longer than a few weeks, parents grow concerned and become anxious. Parents are concerned with the decreased food intake as well as the decreased growth. This type of resistant eater tends to be more interested in play than in eating. They may take a few bites of food and then refuse any more. Other behaviors that may be exhibited are refusal to open their mouth, spitting out the food, throwing the utensils or food and attempting to leave the area. The parents try to coax the child, slip food into his or her mouth when the child is distracted, threatening him/her and/or attempting force feedings. However, this parent becomes stressed, anxious and exhausted. If these resistant eating behaviors become extreme, then the child may be diagnosed with infantile anorexia. Field et al., (2003) classified this type of resistant eating behavior as a “motivationally based feeding problem” while Crist & Napier-Phillips, (2001) refers to the child’s behaviors of negotiating, refusing to eat or leaving the table as an underlying behavioral issue.

Chatoor & Ganiban, (2003) labeled another form of resistant eating as selective food refusal or sensory food aversions. In this form of resistant eating, toddlers consistently refuse to eat certain tastes, textures or odors. This behavior becomes apparent when the child transitions from formula/breast milk to baby food and table foods. This pattern of eating can range from mild to severe and can cause parental concern and stress in the family during mealtime especially when the child will only eat a select few foods. Behaviors elicited from these resistant eaters can be gagging, vomiting or the spitting out of food. These children tend to generalize their aversion
to foods so if the child does not like peas, then other green food will be avoided. Other behaviors are refusing to eat if the undesired food touches another food, or if it is on the same plate. Some children will not tolerate it on the table. Some children will eliminate food groups such as fruits and vegetables or meats. When the problem has become this severe, the child is at risk for specific nutritional deficiencies. If the child only prefers soft or pureed foods, then that lack of experience of chewing has not developed and oral motor skills may be delayed. This pattern of resistant eating may develop into either skill based or structural abnormalities if the child’s oral structures do not develop (Crist & Napier-Phillips, 2001; Field et al., 2003).

The third type of resistant eating identified by Chatoor & Ganiban, (2003) is the post traumatic feeding disorder is the fear and refusing foods because of a past experience of choking. The food avoided can be either a solid-based or liquid-based depending on which type triggers the traumatic event. At times parents have reported that this pattern of eating resulted from intubations, nasogastric tube feedings or after major surgery that required oropharyngeal suctioning. The parents report that due to the traumatic event, the child was distressed and may associate these fears with their feedings. When the child is positioned for feeding, these fears may be elicited and the child may arch, cry or refuse to open his/her mouth. Crist & Napier-Phillips, (2001) referred to this resistant eating as behavioral issues that are based on emotional issues.

Resistant Eating in Children with ASD

Children with ASD usually have less than 15 foods that they will eat and frequently leave out foods from certain food groups. The food groups that are frequently omitted are vegetables and fruits and usually limit proteins to a select few. These children tend to crave carbohydrates such as bread, sweets, chips and other starchy foods. These children have rigid rituals that when not followed, can create a day of explosive behaviors. They tend to prefer certain brands, specific preparation, specific presentation – such as the same plate, with the same utensils and the same cup (Ernsperger & Stegen-Hanson, 2004).

Some studies (Schreck & Williams, 2006; Schreck et al., 2004; Williams et al., 2000) state that children with ASD have rigid ritualistic behaviors and routines that dictate which foods
are accepted and/or refused. Food refusals may be a result of the way the food is presented, if one food is touching another, which utensils are provided and where they are placed, how the food was prepared and/or whether a particular brand of food was served. The temperament of the child when he or she was an infant is also believed to impact the ASD child’s food preferences. Poor social skills also influence how the child eats, as many parents indicated that the child ate differently in diverse environments.

Field et al. (2003) also found that children with ASD were more resistant with the type and the texture of food they chose to eat and thereby narrowing their choice of foods that are nutritionally appropriate. These children, the study found, would only have a few choice foods that the child would consistently eat and would refuse all others including whole food groups.

Bennetto, Kuschner, & Hyman (2007) indicated that feeding difficulties (resistant and atypical eating patterns) are a common occurrence within the ASD population with a 70-90% incidence rate and may be due to inaccuracies in smell and taste. This study found that children with ASD have difficulty identifying basic smells and tastes. The interaction of accurate tastes and smells can impact the child’s selection of novel foods and food associations. If the ASD child has inaccuracies with this interaction, then this may impact the food choices made.

Twachtman-Reilly, Amaral, & Zebrowski (2008) indicated that there were two physiological issues that impact the ASD child’s eating behaviors: gastrointestinal issues and sensory processing issues. There has been some speculation that gastrointestinal issues is associated with resistant eating patterns however, the study by Black, Kaye, & Jick, (2002) found that children with ASD were no more likely to have gastrointestinal issues than children without ASD before their diagnosis of ASD. While other studies Fields et al. (2003); Williams et al. (2000) indicate a link between children with ASD and gastrointestinal issues. However, there are those children with ASD that present with gastrointestinal symptoms such as GERD (gastro-esophageal reflux disease), constipation and diarrhea. These children are frequently unable to identify the source of their discomfort and thereby, refuse many types of foods to alleviate their discomfort. Their inability to communicate effectively, identify pain, discomfort or hunger often leads to frustration which usually manifests itself in behaviors issues (Fields et al., 2003).
The other physiological issue identified by Twachtman-Reilly et al. (2008) is the sensory processing issue. Children with ASD have been identified with sensory processing disorders through the use of the Sensory Profile (Dunn 1999) a standardized caregiver questionnaire that measures the child’s responses to sensory events in everyday life. On the Sensory Profile there is an area identified as oral sensory processing. It is in this area that children who restrict or limit their foods usually score low in indicating that type, temperature and texture of foods and smells can impact their food choices. Other areas identified on the Sensory Profile that impact the child’s selective eating are auditory processing and touch processing. These three areas can indicate that the child’s ability to modulate sensory input is impacted by hypersensitivity, hyposensitivity or fluctuating responses which results in atypical responses of sensory seeking or avoiding behaviors. It is these atypical responses that may directly or indirectly impact his or her resistant eating patterns.

The child with ASD is complicated and puzzling and the resistant eating patterns cause concern and anxiety for the parents. The stress of raising a child with ASD is further complicated when that child is so restricted in his or her food preferences that it causes parental concern for the child’s nutrition and growth. This may be in part why many parents provide their children with vitamin therapy. The family of an ASD child may be further stressed by the lack of social and family outings due to the child’s behavior and/or his or her ritualistic behaviors that may impede their meal.

**The Sensory System of ASD Children**

Deficits in sensory processing can be considered mild, moderate or severe in either hypersensitivity or hyposensitivity to sensory stimuli. Children with ASD usually have difficulty processing sensory information such as movement, taste, touch, sight, smell and sound. Some researchers have found as many as between 30% and 100% of children diagnosed with ASD have some kind of sensory processing difference (Kern, Trivedi, Grannemann, Garver, Johnson, Andrews, Savla, Mehta, & Schroeder, 2007; Leekam, Nieto, Libby, Wing, & Gould, 2007; Watling, Deitz, & White, 2001). The areas of sensory differences that were commonly identified were tactile defensiveness, auditory, olfactory and/or gustatory hypersensitivity. High and low
thresholds were noted as well as inappropriate responses and differences in modulation of the sensory input. Leekam et al., (2007) found that 94% of the sample population had sensory differences on the Sensory Profile as compared to the 65% in her clinical comparison group especially in the areas of taste and smell sensitivities. However, Kern et al., (2007) found that the significant correlation only holds true for those who are 3-12 years of age. Children and adults with ASD older than 12 years of age did not exhibit a significant correlation between sensory differences and the severity of ASD.

Sensory differences are described as the information brought in by the senses that are not processed accurately and as a result the child misinterprets the incoming sensory information. Processing sensory information provides the foundation that is necessary for complex learning and behaviors. Sensory processing refers to the way the brain takes in the information, organizes and interprets it, and then makes a meaningful response. If the child is processing sensory information accurately, this becomes automatic. For example, a parent may be cooking dinner, the child may walk into the kitchen and the information is processed and a response may be elicited. However, a child with poor sensory processing or sensory differences, that same smell may be felt too intensely and bombard the child’s sensory system, compelling the child to respond in a fight, flight or freeze response.

Problems in sensory processing or sensory differences in children with ASD have been clinically observed as well as reported by parents. Sensory differences with high and low thresholds have been observed in auditory, visual, touch, oral and multi-sensory modalities. Abnormal posturing, balance problems, abnormal eye movements and a larger sway may be indicative of poor vestibular responses in children with ASD. Problem in motor control were also noted. Kern et al., (2007) also indicated that children with ASD have either a low or high threshold to vestibular stimuli. Children with low threshold responded to vestibular activities by trying to avoid the activities, while those with the high threshold can be sensory seekers and select intense and frequent vestibular stimulation. Kern et al., (2007) has concluded from the research that these “children with ASD have a comprehensively different sensory processing system.” The ability to process and interpret oral, touch, visual and auditory sensory stimuli and should be considered part of the diagnosis of ASD. (Autism Speaks, 2007; National Education
Association, 2006; Kern et al., 2007; Kern, Garver, Grannemann, Trivedi, Carmody, Andrews, Mehta, 2007)

**Nutrition Concerns as a Consequence of Resistant Eating**

Children who experience chronic food refusal may be diagnosed later with failure to thrive as the child’s height and/or weight are below the fifth percentile in relation to their chronological age. Many children maintain normal growth parameters in spite of their resistant eating habits. However with chronic resistant eating behaviors, the child can develop malnutrition or delayed development. This child can also create family stress as more concessions concerning food and eating habits are made to appease their child’s resistant eating behaviors. (Jacobi et al., 2003; Werle, Murphy & Budd, 1998).

**Parental Stress and Their ASD Children**

Parents of children with ASD tend to have more stress than parents of typically developing children and parents with children with other disabilities. Aggressive behaviors and the child’s behavior while in public are what parents express as the primary reason for their stress (Honey, Hastings, & McConachie, 2005). Other factors contributing to their stress are the intensive therapies and care of their autistic child as well as a lack of motivation for social support and the frequency of social interactions (Duarte, Bordin, Yazigi, & Mooney, 2005). Parents of handicapped children typically have more stress as they need to advocate and coordinate the child’s therapy schedule, make decisions for treatments and have the additional financial burdens. Children with ASD not only cause stress for the parents but also for the other family members. The disruptive anti-social behaviors, tantrums, rigidity in their routines and the obsessive-compulsive behaviors can erode the parent’s self-confidence and increase their feelings of failure and helplessness (Higgins et al., 2005). In addition to these stresses, if the ASD child has poor eating habits as most resistant eaters do, the parents may feel increased stress and inadequacy to provide for their child’s nutritional well being.
Introduction

This chapter presents the research methodology of this proposal. The research questions were presented. The sample, instrumentation, procedures, and data analysis were described.

Research Design

This investigation of resistant eaters and children with a diagnosis of ASD was a qualitative investigation using in-depth interviews of the parent(s) to understand their child’s self-imposed limits on the food choices and behaviors and the impact it has on the family, their mealtimes together and the social time spent as a family. The phenomenological approach was used. This approach allowed the researcher to discover and analyze the subjects’ family experience, learn how they interpreted those experiences, and how it developed to create their view of the world.

Research Questions

1. What mealtime behaviors are perceived by the families of ASD children with resistant eaters?
2. What commonalities and idiosyncratic behaviors are observed by the families in their children at mealtime?
3. What are the experiences of families of children with ASD who have resistant eating behaviors?

Participant Selection

The participants were chosen from preschool to second grade from a central Ohio area. This area was chosen out of convenience. Coworkers, teachers, therapists and other area
providers made recommendations of children for study participation. A screening questionnaire was completed by the parents of the recommended participant.

The inclusion criteria were that participants:

1. were between the ages of 4 and 8 years of age
2. had a diagnosis of ASD, PDD, PDD-NOS or Asperger’s Syndrome
3. were reported to eat less than 15 preferred foods.

The exclusion criteria were:

1. co-morbidity of another diagnosis such as Fragile X, seizure disorders, ADHD, Down’s Syndrome etc.
2. adherence to any restrictive meal plans such as gluten free and casein free diets.
3. prescription medication of Risperdal or Risperdone

**Sample Size**

A sample size of 10, or until a saturation of data was achieved, with a distribution of 8 boys and 2 girls was representative of the number of boys versus girls that are diagnosed with ASD.

**Instrumentation**

The instrument used was the interview questionnaire. It consisted of a series of open-ended questions with additional probes that were based on the literature review and the research questions. This instrument was reviewed by a number of experts in the field, as well as by two other colleagues and a parent. Use of the literature review was used to validate the instrument. A pilot study was also utilized to determine if the instrument was parent friendly and if it addressed the issues. The instrument was administered through the use of open-ended questions that were recorded with audio tape and written notes.

The Sensory Profile developed by Winnie Dunn is a standardized caregiver questionnaire for children between 5 -10 years of age (with adaptations for 3-4 year old children), that evaluates
how the child is processing, modulating and responding to sensory information in everyday life through 125 questions. The population the questionnaire is scored in the following categories

**Typical Performance:** Child obtains scores at or above 1 standard deviation below the mean score indicating typical sensory processing abilities. This range indicates the child performed better than the lowest 16% of the research sample of children from which the assessment tool was developed.

**Probable Difference:** Child obtains a score between 1 and 2 standard deviations below the mean. Section raw scores in this range indicate questionable areas of sensory processing abilities. This range indicates the child’s performance was between the 2nd and 16th percentile of scores in research sample of children from which the assessment tool was developed.

**Definite Difference:** Child obtains scores below 2 standard deviations below the mean, indicating sensory processing problems. This range indicates that the child is performing like a child in the lowest 2% of the research sample of children from which the assessment tool was developed. This evaluation tool was used to provide a description of the sample.

Also a three-day food diary was to be completed before the interview was used to describe and validate the child’s resistant eating behaviors.

**Procedures**

Once the subjects have been identified, interviews were scheduled with the primary caregiver or with both the mother and the father at a time that was convenient for both parties and when the interview could be completed free of distractions. The interviews were scheduled in the home during a time the parent anticipated that the child would be eating a snack or meal. The child was observed during the snack or meal with the focus on the parent-child interaction. The parents were asked open ended questions to learn about the family’s story. These interviews were tape recorded and transcribed verbatim. The individual interviews were combined in a word file that was analyzed to determine the commonalities between the families. The parents were called a second time for follow up to clarify the information from the interview and the observation. The phenomenological approach was utilized to acquire information about what these parents experience and to define the common characteristics between the families interviewed. It was hoped that through the phenomenological focus that information could be obtained about these
children and families that could be presented as shared experiences to enhance the understanding of the impact these children and their behaviors have on the family.

**Data Analysis**

Using the transcriptions of the interviews and field notes, the data were examined for commonalities between families and the common themes were identified among the interviewed families. Phone calls to the families following the interview and verifying critical issues to determine if the parent agrees with the interpretations of the interview were used as a validity check. The researcher explored the issues and understood the phenomena by taking the unstructured data and discovering patterns, identifying themes, gleaning insight and developing meaningful conclusions. Data were organized by topic including; transcripts, content labeling and files developed by topic or category. These categories were analyzed to develop themes which helped determine the commonalities among the families and the children. In addition, the Sensory Profile was completed by the caregiver and a food diary from the past three days was obtained from the parents prior to the interview. These data were used to describe the sample and to validate their eating problems.

**Methods for Establishing Trustworthiness**

One method of triangulation was to have the caregiver complete the Sensory Profile to document a sensory processing disorder. Observations of eating and the interview were used as data sources for understanding the feeding experience. Additionally, the use of personal knowledge of the subjects, teacher reports and a three-day food record from the parents provided data from different sources to strengthen the design of the study. Interpretation of the parent s’ interviews were checked and validated during the second phone call.
ASD is a neurobiological condition that affects the social interactions and communications skills of an individual as well as the presence of unusual behaviors or interests (Autism Speaks, 2007; Bowers, 2002; Lukens, 2005; National Education Association, 2006). Also associated with ASD are the rigid routines and repetitive behaviors as well as the child’s ability to regulate and process sensory information. At age three a reliable diagnosis can be made but children have been diagnosed as early as six months of age (Autism Speaks 2007). Children with ASD have similar characteristic behaviors that affect each individual but the combination and varying degrees of severity as well as their behaviors and rituals manifest differently in each child.

ASD children often demonstrate stereotypic behaviors, i.e., restricted, repetitive and/or stereotypic patterns, interests or activities. They develop rituals in routines that can be highly rigid or can be more subtle, as when a child only eats certain brands of food. They may have repetitive movements, peculiar reactions to sounds or movements, odd visual behaviors or tactiley inspect items or foods. (Albon, 2005; National Education Association, 2006; Tankersley & Cown, 2007; William et al., 2005).

Since many children with ASD do not regulate and process sensory information in a typical manner, it can affect behaviors and social interactions and specifically impact their eating. These children may restrict or limit certain foods, food groups or textures from their diet. Approximately 25% of typically developing toddlers and preschoolers are considered picky at this age and the pickiness is typically a transient problem (Chatoor & Ganiban, 2003; Ferreri et al., 2006; Timimiet al., 1997; Williams et al., 2005). As many as 80% of special needs toddlers and preschoolers have transient problems with limited food selections. Children that only eat fifteen foods or less are considered resistant eaters (Ernsperger & Stegen-Hanson, 2004). If the condition lasts longer than two years, it is considered chronic and if the problems are not addressed these behaviors are likely to continue. Long term exposure to resistant eating may
increase the risk for medical and nutrition-related problems. (Kern & Marder, 1996; Nicholls et al., 2001; Williams et al., 2000)

**Pickiness in Eating with Typically Developing Children**

For children between the ages of one to three, getting their necessary nutrients can be challenging. Food jags are common and refusal to eat new foods may also occur because they think they will dislike it or are afraid of it. However, with typically developing children the more frequently the food is presented, the more the child becomes familiar with it and is more accepting of the new food (Ernsperger & Stegen-Hanson, 2004; Jacobi et al., 2003; Lewinsohn et al., 2005; Skinner et al., 2002). This is not the case for children with ASD.

**Resistant Eaters:**

Jacobi et al. (2003) described resistant eaters as consuming a limited number of foods, unwilling to try new foods, avoiding certain food groups and having strong preferences for certain foods. Jacobi et al. (2003) also found that resistant eaters exhibited a decreased number of sucks as early as the first few months of life, tended to be those children who relied on formula for nourishment while breast-fed babies were more accepting of new foods. Resistant eaters also limited the variety in their fruits vegetables and sweets (Higgins et al., 2005) while typically developing children ate a variety of foods.

Chatoo and Ganiban (2003) refer to three types of food refusal: unpredictable food refusal, selective food refusal or sensory food aversions and the third group is the post-traumatic feeding disorder. The first one, the unpredictable food refusal is identified by the extreme inconsistencies in the child’s preferences as well as caloric intake. As an infant the child is more interested in looking around than eating and consuming only small amounts of breast milk/formula and as a result had frequent feedings. This may occur as early as 6 months but usually starts at 9 and 18 months of age up to age three and usually occurs during the transition from spoon feeding to self-feeding. This type of resistant eater is more interested in playing than eating and may take a few bites and then refuse any more, refuse to open his or her mouth, spit out the food, throw the utensil or food or attempt to leave the area. The second type identified was the selective food refusal or sensory food aversion. This is where the child consistently refuses to
eat certain tastes, textures or odors. This is more apparent when the transition from breast milk/formula to baby food and table foods. This can range from mild to severe and can cause the parent stress especially during mealtime when the child will only eat a few select foods. Behaviors observed from these resistant eaters can be gagging, vomiting or spitting out the food. They also will generalize their aversions so if they dislike peas then they will not eat any green foods. Other behaviors are refusing to eat it if an undesired food touches another food or if it is on the same plate. Some children will eliminate food groups such as fruits, vegetables or meats.

Feeding problems are a result of several factors that probably interact with each other. (Ahearn et al., 2001; Crist & Napier-Phillips, 2001; Ferreri et al., 2006; Field et al., 2003; Luken, 2005; Whiteley et al., 2000; William et al., 2005) The three factors are biological, behavioral and social. Biological factors include structural abnormalities such as cleft palate, neurological conditions, cardio-respiratory problems and unusual sensory processing skills (Chatoor & Ganiban 2003, Luken 2005, William et al., 2005). Behavioral factors were closely tied to psychosocial issues such as dysfunctional interactions between parent and child, emotional difficulties and negative feeding behaviors. Social factors were seen as the child’s inability to eat with others and later lead to social anxiety. Chatoor and Ganiban (2003) suggested that these eating behaviors were familial genetic traits and if parents were resistant eaters, the child would be offered less variety in food selections which is considered the underlying reason for the child’s restrictive food choices.

Resistant Eating in Children with ASD

Children with ASD usually have less than 15 foods that they will eat and frequently leave out certain food groups. Fruits and vegetables are usually omitted with a select few from the protein group. They tend to crave carbohydrates such as bread, sweets, chips and other starchy foods. They also have rigid routines that when not followed can create explosive behaviors. They also prefer certain brands, specific preparations, specific presentation such as the same cup and plate and specific utensil (Ernsperger & Stegen-Hanson, 2004).

Some studies (Ahearns et al., 2001, Crist & Napier-Phillips, 2001; Lukens, 2005; Nicholls et al., 2001; Shreck & Williams, 2006; Timimi et al., 1997; Whiteley et al., 2000;
Williams et al., 2000) indicate that the ASD child becomes a ‘super taster’, a physiological reaction causing the tongue to have an extreme sensitivity to bitter taste that results from their tendencies to only eat sweets and carbohydrates. The taste buds in the tongue do not experience the sweet taste and therefore they crave more sweets.

Other studies (Schreck & Williams, 2006; Schreck, Williams, & Smith, 2004; Williams et al., 2000) state that these children have rigid ritualistic behaviors that dictate which foods are accepted and/or refused. Food refusals may be a result of the way it is presented, if a food is touching another, what utensil is provided, how it is placed, how the food was prepared and if a particular brand of food was used. Field et al. (2003) found these children were more resistant with the type and texture of the foods they chose to eat and thereby narrowing their choices that are nutritionally appropriate.

Bennetto et al. (2007) indicated that resistant eating patterns occur in the ASD population with a 70-90% incidence rate and may be due to their inaccuracies in smell and taste. This study found that these children have difficulty identifying smells and tastes and the interaction of accurate tastes and smells can impact the child’s selection of novel foods and food associations.

Twachtman-Reilly et al. (2008) proposed that there are two physiological issues that impact the ASD’s child’s eating behaviors: gastrointestinal issues and sensory processing issues. The speculation that gastrointestinal issues are associated with resistant eating is controversial as the study by Black et al. (2002) found that children with ASD were no more likely to have gastrointestinal issues than children without ASD. While other studies Fields et al. (2003) and Williams et al. (2000) indicate a link between children with ASD and gastrointestinal issues such as GERD, constipation and diarrhea. Because these children do not seem to identify their source of their discomfort, they refuse many types of foods to alleviate the discomfort. Their inability to communicate effectively, identify pain, discomfort or hunger often leads to frustration which manifests itself in behaviors issues.
The Sensory System of ASD Children

Deficits in sensory processing can be considered mild, moderate or severe in either hypersensitivity or hyposensitivity to sensory stimuli. Children with ASD usually have difficulty processing sensory information such as movement, taste, touch, sight, smell and sound. Some researchers have found as many as between 30% and 100% of children diagnosed with ASD have some kind of sensory processing difference (Kern et al., 2007, Leekam et al., 2007; Watling et al., 2001). The areas of sensory difference that were commonly identified were tactile defensiveness, auditory, olfactory and/or gustatory hypersensitivity. Leekam et al. (2007) found that 94% of the sample population had sensory differences on the Sensory Profile especially in the areas of taste and smells.

Children with ASD have been identified with sensory processing disorders through the use of the Sensory Profile (Dunn 1999) a standardized caregiver questionnaire that measures the child’s responses to sensory events in everyday life (Twachman-Reilly et al., 2008). Children who restrict or limit their foods usually score low on oral sensory processing, indicating that type, temperature and the texture of foods and smells can impact their food choices. Other areas on the Sensory Profile that were found to relate to eating behaviors are auditory processing and touch processing (Twachman-Reilly et al., 2008). These three areas can indicate that the child’s ability to modulate sensory input is impacted by hyper or hyposensitivity or a fluctuating response which results in atypical responses of sensory seeking and avoiding behaviors. Children that have sensory avoiding behaviors are more likely to exhibit pickiness in their eating behaviors since the child will try to avoid touching a food that could be aversive to the touch. These children do not explore their food with their hands or mouth and as a result become more restrictive in their food choices.

Impact on the Family

Nicholls et al. (2001) and Timimi et al. (1997) indicate that resistant eating behaviors impact the family and can become a major family crisis. Often the child is viewed to be manipulative and the parents may feel resentment or doubt their ability to parent. Parental strategies such as making multiple meals reduced the number of tantrums and behaviors associated with mealtime as well as a way to insure the child had some nutritional intake. Parents
also express that their child eats differently depending on the situation. Social situations, family situations and eating at a restaurant have different effects on the child’s eating behaviors. Behaviors associated with mealtime included whining, crying, gagging, resisting self-feeding, spitting food out, leaving the table, refusing to come to the table, pushing or throwing the food, inconsistent eating schedules or use of idiosyncratic behaviors such as using the same utensil/plate/cup, foods not touching or specific food preparations. (Ahearns et al., 2001; Ferreri et al., 2006; Field et al., 2003; Lukens 2005; Schreck & Williams 2006; Schreck et al., 2004; Timimi et al., 1997). Other parent strategies may include coaxing, negotiation, and in rare instances threats and force feedings: (Crist & Napier-Phillips, 2001, Williams et al., 2005; William et al., 2000). Parent-child communication can be met with conflict and resistance when centered around feeding and eating behaviors (Nicholls and Bryant-Waugh, 2009). As the child reaches the middle childhood ages, parents often have “given up hope of changing their child’s eating habits” (Timimi et al., 1997).

**Nutrition Concerns as a Consequence of Resistant Eating**

Nutritionists state that a diet high in fiber and rich in fruits and vegetables will prevent cancer, diabetes, heart disease and other long-term health issues, however, the lifelong studies of nutritional intake and disease prevention has not been conducted. Resistant eaters take in fewer nutrients than their peers, and tend to eat the starchy high-fat carbohydrates increasing their risk of obesity (Tarkan, 2005). Children that experience chronic food refusal may later be diagnosed with failure to thrive as the child’s height and weight are below the 5th percentile in relation to their chronological age. However, many children maintain a normal growth pattern despite their resistant eating habits. The ASD child also creates family stress as more concessions concerning food and eating habits are made to appease the child’s resistant eating behaviors (Jacobi et al., 2003; Werle et al., 1998). Parents express guilt, concern and stress because their child’s nutritional intake appears inadequate. They may try to supplement their diets with vitamins. Extended family members may make unkind comments about the child’s restrictive eating behaviors and may also indicate that it is a result of poor parenting skills. This again causes undue stress on the parents.
Parental Stress and Their Children with ASD

Parents of children with ASD tend to have more stress than parents of typically developing children and parents with other disabilities. Aggressive behaviors and their behaviors while in public are what parents express as the primary reason for their stress (Honey et al. 2005). They may be stressed by the lack of social and family outings due to the child’s behavior and or his/her ritualistic behaviors which may impede a meal. Other factors of their stress are the intensive therapies and the care of their child with ASD and a lack of social support (Duarte et al. 2005). Parents typically coordinate their child’s therapy schedule, make treatment decisions, advocate for their child and endure additional financial burdens. Children with ASD not only cause stress on the parents but on other family members as well. The disruptive anti-social behaviors, tantrums, rigidity in their routines and the obsessive-compulsive behaviors can erode a parent’s self confidence and increase their feelings of helplessness and failure (Higgins et al. 2005). In addition to these stresses, if the ASD child has poor eating habits as most resistant eaters do, the parents may feel increased stress and inadequacy to provide for their child’s nutritional well being.

The significance of the problem is that the families have very few positive or successful strategies to help their ASD children become more accepting of a variety of foods and to be less rigid in mealtime behaviors and patterns. By gaining a perspective on the influences of the child’s resistant eating behaviors and its impact on the family and how they have learned to cope with family outings and daily routines may allow the therapist to develop strategies and identify new treatment techniques.

Method:

The research design of the study of resistant eaters and children with a diagnosis of ASD was qualitative; using in-depth interviews of parent(s) to understand their child’s self-imposed limits on the food choices and behaviors and the impact it has on the family, their mealtimes together and the social time spent as a family. The phenomenological approach was used. This approach allowed the researcher to discover and analyze what the participants’ families experience and how they interpret those experiences to create their view of the world.
Research Questions:

1. What mealtime behaviors are perceived by the families of ASD children with resistant eaters?
2. What commonalities and idiosyncratic behaviors are observed by the families in their children at mealtime?
3. What are the experiences of families of children with ASD who have resistant eating behaviors?

The participants of the study were the primary caregivers of seven children with a caregiver-reported diagnosis of ASD and between the ages of 4 and 8 years. Primary caregivers completed a screener to identify their children’s intake, including restrictive meal plans such as the gluten free or casein free diets, herbal supplements or prescription drugs. The screener also provided a feeding and eating history of the child. (see appendix A) Participants were recruited from the recommendations of therapists, teachers and co-workers from a suburb located in central Ohio.

After the screener was completed, the primary caregiver was given a three-day food journal (see appendix B) to complete before the interview to describe and validate the child’s resistant eating behaviors. The completion of the Sensory Profile was also requested of the primary caregiver. The Sensory Profile (Dunn, 1999) is a standardized caregiver questionnaire for children between 5-10 years of age (with adaptations for 3-4 year old children) that evaluates how the child is processing, modulating and responding to sensory information in everyday life through 125 questions. This evaluation tool was used to provide a description of the participant’s sensory processing.

Procedure

This study was approved by the Institutional Review Board of the Ohio State University and after the subjects were identified, an interview was scheduled with the primary caregiver. The interview (see appendix C) was developed by the author based on her experience working with the families and their children and a review of the literature. The interviews were scheduled in the
home during a time the caregiver anticipated that the child would be eating a snack or meal. The child was observed during the snack or meal with the focus on the parent-child interaction. The parents were asked open ended questions to learn about the family’s story. Interviews were tape recorded and transcribed verbatim. The individual interviews were combined in a word file that was analyzed to determine the commonalities across the families. A follow-up call was placed to clarify the information from the interview and the observation.

Data Analysis

The data from the interviews transcriptions and the field notes taken during and after the observations of the child were used to examine the commonalities among the families and identify themes that were common. After the interview, the families were called back to verify critical issues to determine if the parent agreed with the interpretation of the interview. This was utilized for a validity check. The researcher explored the issues and examined the unstructured data to discover patterns, identify themes, glean insight and develop meaningful conclusions. This researcher organized the data by the following topics; behaviors, rituals, preferred foods, parent attitudes, gastro-intestinal issues and extended family concerns. Additional categories of techniques used to increase number of preferred foods and allergies were examined. Then under those topics common themes were identified. The information gleaned from the three day food journal and the Sensory Profile was used to describe the sample and validate their eating behaviors.

Methods for Establishing Trustworthiness

The completion of the Sensory Profile and the three day food journal were used to document sensory processing disorders and further describe the participants. The observation of the child eating and the interviews were data sources to facilitate understanding of the feeding experience. Data from different sources such as personal knowledge of subjects and teacher reports helped to strengthen the design of the study. Interpretation of the parent’s interview was checked and the themes were verified during the second phone call.
Results

The names of participants have been changed to protect confidentiality. The following sections provide case reports on each of the participants.

Eli

Eli was 4 year-5 months and was diagnosed with Autism. He was not on any specific diets but did take a multi-vitamin, as well as zinc, cod liver oil, a type of fish oil, coenzyme Q10, calcium and vitamin D. He did not take any medication. The Sensory Profile indicated that he has definite differences for the auditory and oral sensory processing and probable differences in the vestibular processing. In oral sensory processing skills, Eli’s mother reported that he gags easily on food textures, avoids certain tastes that are typical of most children’s diet, will only eat certain tastes and self-restricts his diet to specific textures and temperatures. She reports that he craves rice. In the auditory processing, Eli responds negatively to loud or unexpected noises, frequently covers his ears to protect them from the noises, is distracted and has trouble functioning in a noisy environment, frequently does not appear to tune-in to the speaker and frequently does not respond to his name although his hearing is within normal limits. In the vestibular processing skills, Eli’s mother reported that he seeks out all kinds of movement activities (swinging), twirls or spins and at times will rock when sitting on the floor or in a chair. Mother reports that this area has improved greatly over the year.

Three weeks prior to Eli’s observation of a meal or snack, he began a new feeding program. This new program that Eli’s parents have initiated has increased his food repertoire. However, since his parents are familiar with the struggles of raising a resistant eater, these data were included. Eli sat on a Move n Sit cushion at the table and was provided with two non-preferred foods and one preferred food. He was to take two bites of each non-preferred food before he took two bites of the preferred food. Eli used the fork to stab at the turkey and brought it to his mouth. As he put it in his mouth, he grimaced and used facial expressions to indicate that he did not like the food. He then took two bites of applesauce which again he expressed displeasure through the use of facial expressions. He was then allowed to have two bites of his preferred food, rice. He took two very large bites. This process went on until he completed his
meal, although he decreased the expressions of displeasure with the non-preferred foods. Occasionally he took a few sips through a straw from his apple juice. When he was finished with his meal, he took his plate to the kitchen and put it in the sink. Based on the three day food journal and confirmed with the mother during the interview, Eli would only eat rice or rice and meat mixed together and seasoned with soy sauce, macaroni and cheese, brand specific Ramen Noodles drained of all liquid, mini Oreo cookies, thin pretzel sticks, mini Teddy Grahams, popcorn, grapes and bananas. Since he began his new eating plan, he has added corn and applesauce to his diet. Eli indicates when he is hungry by taking his parents and leading them to what he wants or using the PECS (Picture Exchange Communication System) to tell them what he wants and he would push his food away, run away from the table or say “all done” when he was finished. His mother also indicated that Eli does not exhibit any gastrointestinal issues as his mother described him as having regular bowel movements.

Prior to the new feeding program, Eli displayed inappropriate meal time routines as he would sit briefly at the table and take a few bites of his rice and meat. After a short time, Eli would run back and forth from the table to the television or a favorite toy. If it was something he liked he would feed himself, but if he didn’t really like it, his parents would give him a little on a spoon and then he would run and come back for another little bite or they would chase him with the spoon to get him to eat his food. When he wanted a snack and didn’t get one he screamed, cried and threw himself on the floor. He exhibited food refusal behaviors such as tantrums, pushing plate or utensils away, throwing food onto the floor. He exhibited failure to accept new foods by gagging, crying, whining, spitting and throwing himself on the floor. Obsessive eating patterns (for example, only mini-sized snacks) included food specific preparations (for example, meat had to be mixed with rice).

Eli’s rituals included brand specific foods as he will only eat a certain brand of tortilla chips and ramen noodles. Specific food preparations included well seasoned with spices and soy sauce rice and meat mixed and if not mixed he would only eat the rice, and eggs when cooked with the rice. He also preferred size specific foods as he only eats the mini Oreo cookies, mini Teddy Grahams and thin pretzel sticks and if they are broken they need to be no smaller than half of the pretzel stick. The texture of his food must be only dry foods and when he eats ramen
noodles, the liquid had to be drained. Activities associated with meal time used to include watching television and playing with his toys, however, about two months ago his parents turned off the television.

Eli’s parents stated that they cater to Eli. His father is more easily persuaded by the behaviors and will give in to his whining and crying quicker than his mother. Eli’s mother states that they cook mostly what Eli will eat, because “I mean we were so tired like okay let’s not even fight, let’s just give him what he wants. That was the easiest. …we know he’s not going to starve to death, but …. he has to eat dinner, he has to eat lunch; so we feel like we have to let him eat his food that way he’s not hungry.” Using this strategy, his parents only make one meal instead of one for Eli and one for them. She reported that she used to make something he would not eat and then when he wouldn’t try it, she would give up. She cooked meals that Eli liked. Her husband believes that if she would have continued cooking the “American” type of foods; that he would eventually have eaten them. But when they moved to Hawaii when Eli was eighteen months old, it was easy to get the “lunch plate” which consists of rice and meat, anywhere they went, so Eli was eating this for all his meals, and his mother stopped cooking other type of foods. His mother acknowledged that she feels it is her fault because it was all she cooked for him. Snacks and other food in the house all revolve around Eli’s wants. They give in to his tantrums and demands because “He knows if he asks for a snack and we don’t give it, he’ll tantrum. …. he will be screaming … we’ll just give it to him. Because after a long day of work I’m like, oh my gosh, I cannot hear screaming right now.” If the family wants to go to a restaurant then they only go out to places that they know he will be comfortable and will eat their food, which limits their choices to Asian and Indian cuisine. His mother also reported that she does not let him lie on the floor and tantrum; she picks him up and gives him deep pressure and tries to calm him yet she is conflicted because some books state not to do this, but she doesn’t want him to lie on the floor or ground and cry.

Noah

Noah was 5 years and 5 months old and was diagnosed with PDD-NOS. He does not take any vitamins or herbal supplements and has never been on any special diets. He does not take any
medication. He was enrolled in an eight week Foods, Friends and Fun therapy group to help him learn to accept offered foods that his mother puts on the table and try new foods. After the eight weeks mother reported that she did not see much improvement. The Sensory Profile scores indicate that all areas are within the typical range with the exception of the oral sensory processing area which was in the definite differences. Noah’s skills in oral sensory processing indicate an avoidance of most foods that are typical of most children’s diets. He limits himself to certain foods which can include some fruits, peanut butter and jelly, macaroni and cheese and chicken nuggets. Mixed textures and “clumpy” textures are avoided. Textures of the food dictate whether it is a preferred or non-preferred food.

Noah was observed eating his lunch with his brother. Noah was given a peanut butter and jelly sandwich that was cut in half. He was given a choice of Pringles potato chips and Goldfish crackers; he chose the chips. He was also given a choice of canned diced pears or applesauce; he chose the applesauce. His mother also gave each child one baby carrot, which Noah immediately asked if he had to eat that. When his mother replied yes, he tried to push it away. When she returned it to his plate, he once again attempted to place it away from his area. His mother gave him a stern look and returned it to his area. He moved it to the edge of his napkin and began eating the chips and applesauce. His mother prompted him several times to sit up in his chair. He took a couple of bites his sandwich. His mother asked him to take a bite of the carrot. He pleaded and begged again not to eat it. His mother said “try no hands”, Noah said no and pleaded again to not touch the carrot. When asked by the observer what “no hands means” he shrugged and looked at his mother who told him to show the observer. He put the carrot in his mouth and put his hands up in the air for 10 seconds and then took the carrot out of his mouth. He didn’t want to finish his sandwich so he asked repeatedly “do you want me to get a bellyache?” after some exchanges with his mother, he then finished eating one half of his sandwich, cleaned up his space and went outside to play. He tells his mother when he is hungry and states that he is all done when he is finished. Based on the three-day food journal and confirmed during the interview, Noah eats a variety of canned fruits, apples, green grapes and bananas, chicken nuggets, chicken or turkey deli meat, fried mozzarella cheese sticks at restaurants, yogurt, pudding only if it is white (can be tapioca or vanilla pudding), vanilla soft serve, but recently has had a chocolate shake (with the lid on, so the color was not evident), jelly toast, crackers, chips and Cheetos. Noah does not eat any
vegetables cooked or raw and no other meats except what was listed. Noah’s mother reported that he does not exhibit any gastrointestinal issues. She described him as having regular bowel movements. At the age of 20 months, he was diagnosed with intussusceptions, which is the infolding of the intestine. It is not related to any eating behaviors and the problem has been resolved through a surgical procedure and has not returned.

Noah exhibited appropriate mealtime behaviors in that he sat at the table until he finished his meal. He was a little fidgety. When he was younger and his language was more limited, Noah exhibited inappropriate meal time behaviors such as pitching his utensils across the room and throwing his plate if it had a non-preferred food on it. When he would be in a restaurant his parents kept him in a high chair to keep him in his seat, however, now he will sit at the restaurant but gets antsy after a short time of sitting. Food refusal and/or failure to accept new foods behaviors included pushing it away, placing it on someone else’s plate, crying, whining, begging, screaming and having tantrums. Now, his food refusal and failure to accept new food behaviors consist of stating no, “get it off my plate”, scooting it off his plate into a napkin or onto his mother’s plate. Noah eats his meals very quickly and always is the first one finished eating and as a result he exhibits an inappropriate rate of eating. Noah also exhibits some obsessive eating patterns as he has color specific foods, food preparation needs to have the food look the same way it did when he ate it the first time, shape of the food (will not eat Burger King chicken nuggets because they were in the shape of crowns) and a few brand specific foods.

Noah’s rituals include textures of the food as he cannot tolerate the texture of meat. He can eat some pureed foods, but mashed and ground textures are avoided. Some of his foods are color specific as he will only eat the green grapes, white pudding/soft serve. Specific preparation of the food includes serving him food so it looks like the first time he had it. Kraft macaroni and cheese has a different look from homemade macaroni and cheese, and would not be tolerated because the first time he ate it, it was the Kraft brand. However, he does not have to eat the Kraft brand as long as it looks like the Kraft brand. Shape specific includes not eating Burger King chicken nuggets because they were in the shape of crowns. Noah has a few brand specific foods that include the national brand of cereal bars, but if he doesn’t see the wrapper, and an off-brand looks very similar to the national brand he will eat it. Noah rarely sits in front of the television to
eat as he is expected to sit at the table with his family for at least ten minutes after he finishes his meal.

Noah’s parents do not force feed, they used to, but were told that this was something that they should absolutely avoid so they place the non-preferred foods on his plate and present him with new foods. They try to get him to do the “no hands” strategy or the take a bite and spit it out; “…and honestly I would guess 50% of the time he’s willing to at least do one of those suggestions that we offer him”, but most of the time she prepares his preferred foods because life with four boys is very hectic and they “don’t have time to fool with it.” However, Noah will exhibit more food refusal behaviors if his father is not home. Noah’s parents have rules about where they eat. Most meals are at the table and he continues to sit at the table for about ten minutes after he is finished eating to spend time with the family. They may eat on the picnic table at times and on special occasions he may be allowed to eat breakfast in front of the television. Friday nights they are allowed to take snacks down to the family room to watch television. Other table rules include using a napkin and using appropriate table language, no screaming and they clean up after themselves. Mother tries to keep a calm voice and treats him like the other boys. If his behavior warrants it, she will send him to the “sad spot” where he will sit for five minutes and usually he will calm down in that time period. Then he will return to the table and put things back, if he has thrown things and tells her he is sorry, because he knows the routine. Some days it takes longer than five minutes. She also uses deep pressure to help calm him. Noah’s mother stated that the impact on the family due to his restrictive eating is “a huge concern. It’s extremely stressful especially at night time when I’m trying to cook and then if he doesn’t want to eat it you have to fix him something else. I mean obviously you could put it there and say eat it or not, and then you’re going to have to deal with it later, all that I’m hungry, I’m hungry, I’m hungry…I don’t eat well therefore I’ve gained weight recently so that’s a huge stressor cause then it just gets worse because it’s easier to just make stuff they’ll eat and that’s all carbs you know…basically. It is very, very stressful”.
Molly

Molly was 5 years and 5 months old and was diagnosed with Autism. She refuses to take a vitamins and does not take and herbal supplements or does not have any special diets. She does not take any medication. The Sensory Profile indicated that she had definite differences in auditory processing and probable differences in oral sensory processing. In the oral sensory processing, Molly avoids many tastes or textures that are typical of most children’s diets. She eats only certain tastes and is picky about the texture of her food. She craves salty and crunchy foods. She licks and chews on nonfood items like toys, pencils and other like objects. In the auditory processing, Molly dislikes loud unexpected noises and at times will cover her ears to protect them from the sound. She ignores the speaker and appears to not be listening; she frequently will not respond when her name is called although her hearing is within normal limits.

Molly was observed during her dinner. She had corn on the cob and apple slices and a sippy cup with milk in it for her meal. Molly was not required to sit at the table and so she would take a slice of apple, sometimes, stuffing it in her mouth all at once, then she ran around the house. She would come back to the table to get another slice or something else. She saw that her sister had a bun so she asked for a bun; she followed her mother into the kitchen to get it. Her father repeatedly asked her to sit down and she started screaming and crying. She stomped her feet and said she wanted to play. Then Molly started singing her ABC’s and ate another apple slice. Every time Molly was asked to sit down and eat her dinner, she threw a temper tantrum and ran from the room. Later she would come back and grab another apple slice or a bite of the bun. Finally Molly picked up the corn, her father coaxed her to take a bite; she screamed and said no and then took a bite. She commented that the corn was rough and she cried with each bite but ate it willingly. She blew on the corn even though it was cold to the touch. Molly sat in her chair for no more than 1 minute and would run around the house, play with her stuffed dog or look at a book as she ate her meal. Her parents report that she does not identify being hungry she just asks for food or she becomes cranky. When she is full, she has been saying all done. Before she could say all done, she would walk away from the table and it was difficult to know if she was done or would be back for more. Based on the three day diet journal and confirmed during the interview, Molly’s preferred foods include; chicken nuggets, turkey bacon, grilled cheese sandwiches,
scrambled eggs, carrots, corn on the cob, apples, applesauce, grapes, pancakes, waffles, toast, quesadilla with cheese, pretzels, chips, Ritz crackers, Doritos, cheese curls, cheese popcorn. Her mother reported that Molly does not exhibit any gastrointestinal issues as she has regular bowel movements and there are no concerns with diarrhea or constipation.

Molly exhibits inappropriate meal time behaviors as she does not sit at the table to eat; she takes some food, stuffs her mouth at times, and runs around the house. Some meals are eaten in front of the television. She has an inappropriate rate of eating as her parents reported that she could take up to an hour to eat her meal if permitted. Food refusal and failure to accept new food behaviors include; no, no, no; no thank you, pushing it away, trying to give it to sister, “here that’s for sister”, screaming, crying, kicking, stomping her feet and running away. She also may throw herself on the floor and bang her head. She also has some obsessive eating patterns such as, specific preparation of some foods and brand specific.

Molly’s rituals include specific preparation of certain foods. Molly expects all her breakfast food to be in a bowl, even if they are pancakes, snack foods are also in a bowl. If she eats grapes they must be presented with half shredded cheddar and half shredded mozzarella cheese in a mound with the grapes on top, eggs are scrambled, apples have to peeled and sliced and at dinner if she is given potato chips they must be in a bowl. Molly has a few brand specific foods such as the Fruit Loops cereal, she prefers the Kroger brand as opposed to the Meijer or Kellogg brand and the only cookie she will eat is a sugar cookie from Walmart. Molly prefers crunchy salty foods and usually prefers dry foods but occasionally has milk on her cereal and will eat applesauce.

Molly’s parents have a regimented sleep and meal schedule as they feel she does better. When her meals are not on time she becomes cranky and has more “meltdowns.” Molly’s mother related that she makes three meals each night; one for Molly, one for sister and one for the parents. The mother expressed concern that if Molly was forced to eat non-preferred foods, she would not eat and she doesn’t want her to be hungry. Mother reported that they give Molly what she wants, they used to try to give her new foods; “but we realized, whatever that rule is 75%, you know 75 times of trying (a new food), we knew it wasn’t going to work with her. …we don’t
usually put things on her plate anymore that she doesn’t prefer or we know she particularly will not eat.” Some days she is curious about a food we are eating; she will look at it but she doesn’t want to taste it and some days they have tried having her “kiss” the spoon with a non-preferred food, but usually she just starts screaming. Mother also stated that if Molly was forced to sit at the table at home, she would eat less and have more behaviors. Mother also indicated that she wished they could go out to eat at a restaurant. Their restaurant dining consists of a trip to McDonalds during a time when there was less business, where Molly can come and go from the table to the play area as she pleases. At a sit-down restaurant, Molly was on sensory overload from all the visual stimuli and the loud noises. She also was unable to roam as she pleased which was distressful for Molly. As a result, the parents do not go out. Molly’s parents do not take her out much because she will tantrum or throw herself on the floor and kick and scream. Even a quick trip to the grocery store can be disastrous. “I don’t know if it’s just kind of an excuse. I’m not, I mean we’re not unhappy it’s just sometimes there are times we think gosh I wish we could go out to dinner, we wish that we could…you know.” Another issue that mother mentioned was they adopted Molly when she was 9 months old and 3 months later she had Molly’s sister. The baby came early due to preeclampsia and mother was given large doses of magnesium sulfate. “My husband calls that my lost year because… that magnesium sulfate causes up to a year of just not being yourself, so I was just kind of freaked out.” That is also the time Molly started not being interested in certain foods that she would eat before. “In my mind it’s all because of these massive changes you know. We brought her home she was just starting to get used to things at our house, then I have a baby, we move her to a different location and to me it’s all my fault.”

Isaac

Isaac was 5 years 11 months and was diagnosed with Autism. He takes a multi-vitamin daily but does not take any herbal supplements and is not on any special diets. He does not take any medication. On the Sensory Profile he showed definite differences in the oral sensory processing and probable differences in auditory, vestibular, touch and multisensory processing. In the oral sensory processing, Isaac avoids certain foods that are typically in children’s diets, he prefers certain tastes and his food has to be at room temperature. Textures of foods are frequently the reason he avoids certain foods. He chews or licks nonfood items at times. In auditory
processing, Isaac responds negatively to loud noises and frequently covers his ears to avoid the noises. He is also distracted by noisy environments and frequently does not tune in to the speaker. In vestibular processing, Isaac seeks out all kinds of movement (fidgeting) and movement activities (swinging) and will twirl or spin throughout the day. In touch processing, Isaac avoids messy activities and expresses discomfort with grooming activities. He is sensitive to certain fabrics and prefers to be barefoot as he becomes irritated by his shoes and socks. He loves to touch people, objects and certain textures and surfaces. In multisensory processing, Isaac has difficulty paying attention, looks away from tasks to notice the action in the room and can occasionally be clingy even in familiar settings.

During the observation, Isaac was having dinner. He had chicken nuggets, baked beans, applesauce and milk. Before dinner, he went out to the kitchen and watched his mother microwave the chicken nuggets. He kept whining about having ice cream, cookies and pudding. Before dinner was ready he went to the bathroom and removed his shirt. His mother stated that Isaac usually eats dinner with his shirt off regardless of the weather. When dinner was ready, Isaac was told to go sit at the table. He sat down in the chair, humming to himself and waited patiently until his mother brought out his dinner. His mother placed some ketchup in the corner of his plate. He took a bite of his chicken nugget and then dipped it into the ketchup and took another bite. Many times he would pick up the chicken nugget with his hand and then stab it with his fork. He ate all his applesauce and then went back to his chicken nuggets. He smelled his baked beans, ate the ketchup and then ate the rest of his chicken nuggets. He asked for more and his mother brought him some. He then smelled the baked beans again and then ate them one bean at a time. His mother gave him a grape, which he looked at and pushed off his plate. She told him to take a bite, he started whining about not wanting to eat it and how he didn’t like it. Mother forced him to take a small bite, and stated he was done. Isaac tells his parents when he is hungry and when he is done. Based on the three day record and confirmed during the interview, Isaac’s preferred foods are French fries, applesauce, salsa, ketchup, grilled cheese, chicken nuggets, macaroni and cheese, hot dogs, peanut butter sandwich, cheese pizza, scrambled eggs, canned fruit but not fresh fruit, cookies, chocolate, pudding, ice cream, cereal; Captain Crunch or Cheerios, chips, pretzels and Cheetos. During the interview his mother reported that Isaac does
not have any specific gastrointestinal issues except that he may experience a little constipation now and then.

Isaac’s behaviors include an inappropriate rate of eating as he eats very quickly, usually in less than fifteen minutes unless it is a non-preferred food. With non-preferred foods, he takes 2-3 small bites in a twenty to thirty minute period. Inappropriate meal time behaviors are that he prefers to stand near the table rather than sit, but will sit for short periods of time; he also prefers to eat with his shirt off but this is a behavior that he only does at home. He may also leave the table but returns if prompted by his parents. These inappropriate meal time behaviors seem to escalate when he is at a restaurant as he prefers to stand at the table and fidget, asks repeatedly to go to the bathroom, becomes very whiny stating “I’m ready to go” repeatedly and on rare occasions crawls under the table. Food refusal and/or failure to accept new foods include whining, begging, stating no or no thank you, taking a bite and spitting it out and feeding it to the dog. His mother reports that he does not really have tantrums they are more like “quiet screams” and sometimes “moans” then he is told if he doesn’t stop he will need to go to his room. Isaac has a few obsessive eating behaviors which include specific food preparation and textures of the foods.

Isaac rituals mostly revolve around the texture of the food and specific food preparation. Isaac seems to prefer to get his food in his mouth with as little interaction as possible especially if it is a messy food like pizza. Isaac likes to have his sandwiches and pizza slices cut into quarters so he can pick it up and place it on his fork. He also likes having wipes available throughout the meal so he can wipe his hands frequently, especially when food gets on his hands. He does not like messy foods but will eat it, especially if it is pizza. He prefers soft textures of foods but not all soft foods as he doesn’t like mashed potatoes or cottage cheese to name a few and he avoids most crunchy foods that take time to chew. Other specific meal preparation activities include placing ketchup on the corner of his plate which he eats after he is done dipping his nuggets or hot dogs. His pretzels or other snack food should not be placed on his plate but onto the napkin beside his plate. Isaac also smells his food before he takes a bite, especially new foods. He tends to play with new foods appearing to explore it. Every Saturday morning, Isaac must have chocolate milk with his breakfast.
Isaac’s mother reported that Isaac and his sister eat first usually because they are hungry and cannot wait. So she cooks them dinner and later the parents may eat a similar meal of something with more vegetables. “A lot of the times we do have separate meals, only because they get hungry when we get home.” His mother reported that they place food on his plate and tell him he needs to try this. He needs to at least try 1-2 bites. Mother provides with options but stands firm on his choices. She states that she tries not to give in to his whining but some days she will give him a half of a cookie instead of a whole cookie and that will quiet the whining for a while. They also bribe or coax him to eat something he doesn’t like. He eats spaghetti and hamburgers when bribed or coaxed but it generally takes a much longer time to get him to eat a small amount. “….. my thing is if he’s hungry enough, he’ll eat it. And we’ve sat down with him and we pushed him, ‘if you want to do this, you’re going to have to eat it’. And at the end of the night, I did make him, he ate a couple bites.” However, if there is something that Isaac doesn’t like, sometimes, his father will get up and make him a sandwich and mother feels that “… he’s just feeding into it. …but overall we tend to give him foods he will eat.”

Cole

Cole was 6 years-8 months old and was diagnosed with Autism. He was not on any specific diets and did not take vitamins or supplements. The medications that Cole takes are Abilify and Xyzol. The Sensory Profile showed that he had definite differences in his oral sensory processing, with probable differences in touch processing and multisensory processing. In oral sensory processing skills, Cole’s mother reported he always avoids certain tastes, self-restricts foods, and craves specific foods, showing strong preferences for certain tastes and particular food textures and temperatures. In touch processing, Cole expresses distress during grooming tasks and dental work. He becomes irritated by his shoes and socks and frequently takes them off. He also strips as he prefers to be naked when at home. He touches people and objects frequently. In multisensory processing skills, Cole has difficulty paying attention, notices all the action in the room even when engaged in a task and walks on his toes.

Cole came home from school, removed his shorts and underwear and went to the kitchen for his snack. He stood by the locked refrigerator and waited for his mother to open it. He helped
his mother microwave the hot dog and then placed it in a bun, squishing it together. He brought his hot dog to the computer and ate it quickly in large bites while playing on the computer. Within fifteen minutes he was back in the kitchen asking for a cereal bar. When he was denied the snack his behavior rapidly escalated to pushing, screaming, and throwing himself on the floor. He was sent to his room and after 5 minutes he came out, calmer. However, as soon as he remembered the snack he was denied, the pattern cycled again. Based on the three day diet journal and confirmed during the interviews, Cole eats only 7-8 foods which include hot dogs, chicken nuggets, grilled cheese, McDonald’s hamburger and fries, cereal bars, mini cheddar rice cakes, pancakes and corn. He does not know when he is hungry or full. As a result, his parents keep the cabinets and refrigerator locked; otherwise he would eat until his preferred foods are gone. During the follow-up phone call, his mother confirmed that Cole does not have any gastrointestinal problem. He used to have difficulty with constipation but not anymore.

Cole uses some appropriate meal time behaviors as he sits at the table during mealtime until he finishes his meal and then puts his dish in the sink. However, inappropriate meal time behavior includes stripping off his shorts and underwear and sitting partially naked at the meal, whether it is at the table or in front of the television or the computer. Other inappropriate mealtime behaviors are exhibited when his parents refuse to give him additional food or snacks. When he is denied a food, he kicks, screams and cries. He also pushes his parents to try to get what he wants. His mother reported that “He’ll throw a fit until he gets something that he wants to eat. Sometimes he’ll stand and hold on to the freezer door and shake it, to where I’m afraid he’s going to pull it over.” Cole exhibits an inappropriate rate of eating as he can finish his meal in 2-8 minutes appearing not to take a breath; unless he is watching television or playing on the computer and then it will take as long as 30 minutes. Obsessive eating patterns include syrup in circles on his pancakes or he won’t eat them and compressing the bread on his sandwiches. He exhibited food refusals and/or failure to accept a new food by gagging, vomiting, kicking, screaming, crying, hitting, pushing, throwing the plate or utensils and removing the non-preferred food from his space.

Cole’s rituals include specific food preparation as his hot dogs have to be cooked in the microwave, the bread on his sandwich is compressed and his pancakes must have syrup circles
otherwise the food will be refused. Other foods can be eaten hot or cold, temperature does not make a difference. He has color specific foods as most of the foods he eats are beige or yellow in color. He must have specific utensils as he only uses the salad fork. Textures of foods need to be crunchy, soft or pureed foods are not tolerated.

Cole’s mother stated that they tend to give in to his tantrums and that she feels it is her responsibility that her family does not eat better. She believes that if the rest of the family ate better, Cole would too. However, she also admitted that she makes a separate meal when a meal consists of Cole’s non-preferred foods. Occasionally they will use bribery to get him to try a new food or will provide him with McDonald’s if he is cooperative.

Jesse

Jesse is 8 years 5 months and was diagnosed with PDD-NOS. He takes a gummy bear vitamin but does not take any herbal supplements and has never been on any special diets. The medication he was taking was called Day-Trana Patch and he has been off it for about 5 months now because it made him very emotional and aggressive. The Sensory Profile indicated definite differences in the areas of auditory, multisensory and oral sensory processing. He had probable differences in the area of vestibular processing. In the oral sensory processing skills, Jesse gags easily on food textures and certain utensils, he avoids most foods that are typical of most children’s diets. Jesse prefers carbohydrates and avoids all veggies and most fruits. His mother reports that he is very picky when it comes to the texture of the food. She also feels he has strong preferences for certain tastes and smells. In auditory processing, Jesse has difficulty completing tasks when a radio or television is on or when the environment is noisy. He hears most background noises and is distracted by the sounds and he does not tune-in to the speaker. In multisensory processing, Jesse has difficulty paying attention, looks away from his task to notice the action in the room and seems oblivious within an active environment. Sometimes he hangs on or seems too clingy even during familiar situations. In vestibular processing, Jesse seeks out all kinds of movement (fidgets and wiggles in his seat) and twirls or spins throughout the day. He does not like activities where his head is upside down.
Jesse was observed during his lunch time with his three younger sisters. Jesse repeatedly asked for a cupcake and when he was told not now, he stomped off. A few minutes later he returned to the area and asked again about the cupcakes. His mother asked him if he would like some pizza. He said yes, and his mother warmed it up in the microwave. He took it to the small table away from his sister and removed all the pepperonis from the pizza and ate them first. He then ate his pizza and a couple slices of salami, drank his cup of water and left the area to play on the computer. He finished his lunch in less than five minutes. Based on the three day diet journal and confirmed during the interviews, Jesse’s preferred foods include mostly “American” foods like rice, fries, pizza, ravioli, hot dogs, turkey, salami or Swiss cheese sandwiches, cheeseburgers, scrambled eggs, sweets like cookies, cupcakes, ice cream and will eat some fruit like strawberries, apples, grapes and bananas. His mother reported that he eats very little Vietnamese food except for just noodles and liquid. He eats no vegetables. Jesse tells his mother when he is hungry or full. Jesse does not experience any gastro-intestinal issues as his mother stated that he has regular bowel movements.

Jesse exhibits an inappropriate rate of eating as he usually eats his meals in 5-10 minutes. If it is a non-preferred meal, he sits and waits, trying to out-wait his mother. He has inappropriate meal time behaviors when he is at a restaurant because he hates to wait and when he is done he wants to leave right away; he frequently leaves the table, asks to the bathroom, and exhibits other restless behaviors. At home, he leaves the table when he is finished eating. Jesse’s food refusal and/or failure to accept new food behaviors include; gagging, spitting it out, crying and screaming, saying “no”, “I hate it” and asking for a different choice. Occasionally he has a tantrum and hits his mother. Jesse’s obsessive eating patterns include food choices based on the textures and specific food preparations.

Jesse’s ritualistic patterns include specific food preparation as he requires the Swiss cheese on his sandwiches to be melted and he will not eat cheese in any other manner. The bread for his sandwiches needs to be white bread, as he does not eat whole wheat bread. When he eats yogurt, it can only be the kind in the tubes. His preferred foods cannot touch non-preferred foods or he will refuse the food. He dislikes most pureed, mashed foods and ground foods with the exception of hamburgers and scrambled eggs.
Jesse’s mother believes that his resistant eating behaviors started when he was three when he had recurrent bouts of tonsillitis. She reported that he was on antibiotics every two weeks and he didn’t talk or eat. “So when he ate anything I felt like I won the lottery.” She says she didn’t know she should use tough love; “I made mistakes.” Jesse’s mother also stated that she prepares a meal for Jesse and a meal for the rest of the family. “Because most of the time I’m with the children. My husband isn’t home much; …and then he comes home two hours later I fix him dinner, so I wash dishes like ten times a day, cook here, cook there; fix this fix that. When a big family comes over with the grandparents of course, so we try to sit at the big table to impress them but it’s hard. It’s very hard. So…family meal time is hard.” Jesse also tries to eat every few hours and if the mother doesn’t watch him, he finds his preferred foods and eats very large servings. At a restaurant, she is constantly reminding him to sit down and they all have to eat quickly so they can leave. “… because it’s like impossible to make him just sit even though he’s already done, but he just doesn’t have that patience.” Jesse’s mother has started using force to get him to eat his vegetables. She gives him a small bowl of vegetables and he will sit at the table and after 15-20 minutes he may take a bite, gagging the whole time. His mother also reported that she has been changing the schedules and she is using more “tough love” telling Jesse he has to eat this food in order to get a reward. “I know I have such a hard time and I blame myself too…I know it’s not too late…. So I’m more tough now. Mean mom, mean mom.” “It is very frustrating as the parent to feel like you are failing.”

Logan

Logan is 8 years and 7 months and was diagnosed with Asperger’s Syndrome and an only child. He takes a chewable children’s vitamin but no supplements and was not on any special diets. The medication he is on is Zoloft. The Sensory Profile indicated that he has definite differences in the areas of auditory, touch, multisensory and oral sensory processing. He has probable differences in visual and vestibular processing. Logan responds negatively to loud unexpected noises and covers his ears to protect them from the sound. He has difficulty with background noises and noisy environments. In touch processing, Logan avoids messy materials, expresses distress during grooming activities and dental work, avoids going barefoot and rubs or
scratches a spot that has been touched. In oral sensory processing, Logan limits his diet to dry, crunchy and salty tastes or foods. He also prefers foods that are beige in color and dark spots found on French fries and chips are removed or thrown away. Logan also chews on his pencils. In multisensory processing, has difficulty paying attention, walks on his toes and leaves his clothes twisted. In visual processing, Logan dislikes bright lights and sometimes covers his eyes, becomes frustrated with puzzles and finding objects in a toy box. In vestibular processing, he seeks out all kinds of movement (fidgets) and movement activities (swinging) and rocks in his chair or on the floor.

During the observation of his meal, Logan ate a bologna sandwich cut into quarters with the crusts removed; Ruffle potato chips, 2 brown sugar cinnamon Kellogg’s pop tarts and Sprite in a cup with a lid and a straw. He was also given applesauce; he refused it, by pushing it away saying no thank you. After several attempts and with encouragement he smelled it and stirred it, gagging several times. His mother reported that his behavior was mild due to the observation. He told his mother when he was finished eating. Based on the three day diet journal and confirmed during the interviews, Logan limits his diet to less than 10 foods; he eats only Oscar Mayer bologna and hot dogs, Lays Ruffle potato chips, Tostitos tortilla chips, Kellogg brown sugar cinnamon pop tarts, Pepperidge Farm pretzel fish, Pepperidge Farm goldfish crackers that aren’t cheddar, triscuits, popcorn, fast food hamburgers (McDonalds or Wendy’s not Burger King due to the sesame seeds on the buns), French fries and occasionally chicken nuggets from Wendy’s. Recently he has begun eating Donato’s subs with just meat and bread. The only foods he eats that have color are yellow lollipops and red Swedish fish. His mother stated during the interview that Logan’s gastrointestinal issues are that he has mild bouts of diarrhea and constipation.

Logan sits at the couch and plays video games or watches television to eat most meals. His parents eat at a later time. His mother described him as a slow eater as he tends to finish his meal within 15 -30 minutes. Food refusal and failure to accept new food behaviors include: his unwillingness to put foods in his mouth, stating no or no thank you, pleading and begging to not to try it. If he puts it in his mouth he will spit it out, gag or vomit. He also cries and screams. Obsessive eating patterns can include eating only beige colored foods; recently, he ate a French
...fry that had a dark spot on it and he gagged and vomited. With certain odors, he will keep his distance and if they sit near him it will be an issue.

Logan’s rituals include brand specific foods as he will only eat certain brands of the foods he prefers and will refuse all others even if they look similar. Logan also requires specific food preparations such as the crusts removed, sandwich quartered, and his pop tarts broken into bite size pieces. He also must either push the buttons on the microwave when his mother makes his hot dog or tell her it okay to push the buttons. He is color specific as all of foods are all beige with the exception of the Swedish red fish and yellow lollipops. Logan also requires specific cup and utensils as his cup must have a lid and a straw and his utensils must be toddler sized. The texture of his food must be dry as he does not tolerate wet foods.

Logan’s mother stated “I’ve accepted the fact that he is never going to eat a fruit and vegetable in his life. I work on just trying to get him to take the occasional vitamin when I can convince him to. So meal times aren’t terrible, he just gets the same foods over and over.” His father is less accepting of Logan’s restrictive eating behaviors and as a result will try to get him to try a new food stating,” look I’m eating this, you’ll like it, you just have to try it.” Logan’s parents continue to present him with new foods and ask him to take a bite and spit it out. This has worked to increase his food repertoire except for fruits and vegetables. Logan’s mother reported that he is eating the same foods he ate as a toddler, with the exception of tortilla chips, potato chips, and the occasional Wendy’s chicken nugget. She feels that peer pressure was responsible for that change. They are not averse to bribing to try to get him to try a new food, stating “That’s the only thing I’ve gotten to work.” The mother continues to make separate meals; one for Logan and herself and one for the father and admitted that she does not cook much. If they go to a restaurant, they never go in without activities to keep him entertained and they pack food for him.

Discussion:

The following themes emerged from the analysis of the transcripts of the interviews and the field notes of the observations. The themes are 1) ritualistic, rigid behaviors seem to be the key to resistant eating behaviors, 2) compromises, 3) how they manage social situations, 4) family stress. Each of these themes will be described in more detail in the following pages.
The children’s ritualistic, rigid behavior seemed key to resistant eating behaviors

Although children with ASD typically select their preferred foods based on texture, color and taste as well as brand, presentation and preparation specifics, other behaviors also can account for their refusals. Behaviors associated with mealtime include; inappropriate meal time behaviors, food refusal, failure to accept new foods, obsessive eating patterns and inappropriate rate of eating and are related to common characteristics of the ASD child. The ASD child’s rigidity of routines, perseverance, sensory processing differences, fear of novel situations and objects and attention to details may help to explain the resistant eating behaviors as rigid routines and behaviors that have been learned (Nichollas et al. 2009). The findings from this study concur with what many other studies have determined about children with ASD and resistant eating. Jacobi et al. 2003 and Higgins et al. 2005 also found that children with ASD have a strong unwillingness to try new foods, consume a limited number of foods and have a strong preference for certain foods as well as a strong avoidance of others. The children in this study all had an unwillingness to try new foods and while most children had fifteen foods or less, some children had a few more but still demonstrated a strong preference for those foods they preferred and a great resistance or avoidance to those non-preferred foods. Researchers (e.g., Field et al., 2003; Higgins et al., 2005; Ernesperger & Stegen-Hanson, 2004) determined that children with ASD tend to eat a variety of dairy, crave breads, grains and other carbohydrates, limit proteins to a select few, leave out certain food groups – mostly the vegetable and fruit group, and have rigid routines that when not followed can lead to explosive behaviors. The participants in this study all limited their protein intake to a select few, craved carbohydrate and omitted fruits or vegetables or would only eat a select few. Other researchers (e.g., Schreck and Williams 2006; Schreck et al., 2004; and Williams et al., 2000) found that rigid routines dictated which foods were accepted or rejected, these routines could be the presentation of the food, if one food was touching another, how it was prepared and which brand of food was used. This study also concurs that the participants all had at least one rigid routine, if not more than one that included brand specific foods, specific food preparation, specific food presentation, color specific, size specific and texture specific and when these routines were not followed some sort of inappropriate meal time behavior would ensue.
Compromises

Jacobi et al. 2003 also stated that children that are resistant eaters are slow eaters, not interested in food, choosey about what they eat and do not consume enough. While Chatoor and Ganiban 2003 determined that resistant eaters were more interested in playing than eating. This study agreed that most of these children that participated were more interested in playing than eating and many (five of the seven) ate quickly in order to get back to playing or would play while eating. Two of the seven participants ran from the table to the toys or television and then would run back to the table to get another piece of food. Most of the families allowed them to watch television or play on the computer for at least one meal a day, while several families allowed the television, computer or video games to be on while eating for all meals. Another compromise that all the families reported was that they make multiple meal preparations for their family members, This was consistent what previous studies have indicated as a way for parents to ensure that their children are getting nutrients (Crist and Napier-Phillips, 2001; Williams et al., 2005). Another strategy or compromise is that they all try to get them to take a bite or lick of a new food. If they take a bite, some will allow them to spit it out, while others will give the child 2-3 bites of food that they must eat. They usually get them to take these bites by bribing, using force, threatening to send them to their room, or waiting them out, this concurs with studies that indicate that strategies parents chose to use included: force, bribing, coaxing and negotiating. Crist and Napier-Phillips, 2001; Timimi et al., 1997; Williams et al., 2005, identified these parent strategies in their studies and suggested that these strategies were frequently unsuccessful. The parents in this study report that they have inconsistent success.

Another compromise is to give them their preferred foods and do not offer the non-preferred foods. Or if they offer non-preferred foods it is occasional. The parents in this study want the child to get the nutrients and said that some days it is not worth the fight or they don’t have time to fight because they have appointments to be kept. Timimi et al. 1997, proposed that by the time the child reaches the age of eight, parents give up on changing their child’s diet. This study found that parents don’t necessarily give-up, but use the strategy of giving in and accepting these behaviors. Molly’s parents stated that “Molly’s very smart, so she understands that at home, we’re not going to press her about that stuff (eating).” Logan, who is 8 years old, his parents are more resigned; “I have pretty much just accepted the fact that he is never going to eat a fruit and
vegetable in his life. So meal times aren’t terrible he just gets the same foods over and over.” Then there are the parents of Jesse, who also is 8 years old, who has decided now is the time for tough love; “So when Jesse was little I didn’t practice tough love…. now he’s willing to[try some new foods], so I feel like I can start doing it now, like press him. So it’s small step.” It appears that the parents of these participants are doing what is best for them and their family, not forcing non-preferred foods so that home life may be a little quieter and/or calmer as opposed to the nightly battle of getting them to eat one little broccoli spear.

The how and why the participants’ parents choose to either “force” or “give in” to their child’s resistant eating behaviors can be as individual as the child. As each family has their own story, their story colors their choice for their child. For instance, Logan’s mother suspected that he had ASD when he was less than one year old because she researched his resistant eating behaviors. She accepted that he is a special needs child as well as a resistant eater, so she makes choices for him that she feels are best for him. “It would just be a new food that we were trying to introduce because we thought well let’s at least expand what we have now.” She has tried to give him a new food: a lick of this, maybe a bite of non-preferred foods and spit it out. Peer pressure has helped, it was how she managed to get him to taste and eventually eat a chicken nugget. Molly’s parents admitted that she eats differently at school and daycare, but they don’t force her at home. They ask her what she wants for dinner and that is what she gets, though she does eat more fruits and vegetables than most resistant eaters. Her mother felt that they just want to make sure she is getting some nutrients, so they provide her with her preferred foods rather than to challenge her with the non-preferred foods. When she was younger they did try more foods but they discovered that she just wouldn’t eat; so allowing her those preferred foods may keep the house a little calmer but they also know that she is eating, and that is comforting to them. Cole was a strong child and when he wanted something, he just pushed to get to it. Providing Cole with his preferred foods has kept peace in the house, unless he is refused a snack or another serving of his food. His mother recognized that his behaviors will need to become manageable before he can over-power them. On the other hand, Jesse’s mother has decided that ‘she made too many mistakes when he was a baby’ and she let him eat what he only his preferred foods. She stated that she was ready to push more non-preferred foods. She mentioned that she tells him if he doesn’t eat the few bites that she gave him of the non-preferred foods; he will have to go to his
room. He never resists so much that he is sent to his room. It takes him much longer to eat those couple bites but she is willing to wait and she is pleased that it is working for her. Eli’s mother has just started a new feeding program and so far it is working. Eli ate foods that he hasn’t eaten since he was eighteen months old. His mother is excited about the prospects of the improved eating behaviors. Ian’s mother also uses what she calls bribery. She will reward him with a special activity or preferred treat if he eats 2-4 bites of the non-preferred foods. Nicky’s mother uses techniques she had learned from his therapy group. She also continues to place the food in front of him, he is unhappy that it is there. He does not tantrum like he did several years ago, he knows the rules and expectations and he knows the repercussions, but they use a “sad spot” that is their time out space where he goes when the need arises. These are all examples of how these families are making compromises to deal with the resistant eating behaviors of their child.

**How Families Manage Social Settings**

The participants’ parents of this study all stated that meal time behaviors were better at home than when they are in a restaurant. There are several issues the child’s parent needs to consider before they enter the restaurant with their child. First of all, does this place serve food that the child will eat? If not, then the parent will need to pack the child’s food. How long is the wait, is another question they must answer. Most of the participants were unable to wait and if they can it needs to be a brief wait. Some parents go to dinner on the “off hours” to assure that they do not have to wait for a seat and that the food is delivered quickly so the child does not have to wait long. The next issue may be harder to answer until they walk in the door, as the parents need to consider the effect of lighting, décor, smells, how loud is it and the size of the crowd. Parents admitted that they avoid going to restaurants because the stress it puts on the child as well as the family. The ASD child has difficulty sitting and waiting for their food and then when they are finished eating the child is ready to leave. They describe the child as antsy, fidgety and a need to move. So the family either needs to entertain the child with crayons, toys and other activities they have brought along or distract the child with walks, trips to the restroom. Extreme cases were that a parent takes the child out to the car while other family members are finishing their meals, or some will just grab and go while the other parent pays the bill. If these distractions were not done, then the ASD child’s behavior could become disruptive. One parent mentioned that they only eat at restaurants that they know their child can tolerate. Another parents’ idea of
eating out is a trip to McDonalds drive-thru; “… but there’s some nights we just look at each other and say I wish we could go out to eat, I wish we could all sit in a booth.” Some families do attend social events but do so without the child or may have to cancel if the child’s behavior is terrible. Usually at the some point of the social or family gathering the ASD child is clinging to the parent, hiding in a secluded area, or crying and cranky because it is too much for their sensory system. Parents generally pack food for their resistant eater if they are going to a social or family gathering where they know it will be difficult for the child to find something to eat.

Parents use different strategies depending on the environment. When their child is at home, behaviors such as leaving the table and returning may be a behavior that could be tolerated at home but would be viewed as inappropriate when the child is in a restaurant. However, some parents require that the child sit at the table with the family and even after he is done to remain there for a short time. Noah’s mother believes that by requiring him to have the same appropriate behaviors at the table for home and restaurants, he is better equipped to sit at the table when at a restaurant. Parents who encourage or bribe their child to eat a new food at home are not as likely to challenge their child’s taste buds at a restaurant. Eli’s mother is able to read his cues as they enter the restaurant; if he is softly crying or moaning, she knows that this is a restaurant that they may be able to visit but as they enter the door and he drops to the floor, the parents gently pick him up and returns to the car knowing that this restaurant is not a good choice. What sets off these behaviors could be something as simple as the lighting, the over-stimulating décor, or something less obvious such as the background noises or something the parents have not been able to identify. However, Eli’s parents know that he has such a liking for Indian cuisine that he will accept the low lighting and the crowds just to eat there. However, this is the only place he will tolerate crowds, loud noises and low lighting.

Family gatherings and other social events may be tolerated if the child is given an opportunity to cling to his mother or wander off to a quieter area. Most families indicate that they attend family gatherings with food packed the child’s preferred foods. Isaac’s mother tries to coax him to try new foods at family gatherings with rewards with inconsistent success. Noah’s mother bring food although she usually sees that he is too busy playing to eat, but when he does get hungry she has preferred foods so he too can enjoy the gathering. Molly’s mother admits they are
not very social, and many times, the father and the sister will go out to a baseball game or a movie and mother stays at home with Molly. Molly adjusts as home is comfortable for her. Mother stated that home might be a little too comfortable in that she is happy to be at home even when her sister is going out. Molly’s mother also stated that they have not taken any trips or vacations and a trip to a restaurant is just not possible at this time. Older family members made comments about how their children ate better and it must be the fault of the parent. Logan’s mother received comments about her lack of parenting skills from her mother-in-law. They don’t avoid social situations with them but the fact that they live out of the state does limit their interactions. So for a family with a child that has a resistant eating behavior, to have a social life, it must be well thought out, well planned and changed at a moment’s notice. Going to a restaurant or a family or social gathering isn’t a spur of the moment activity and as a result usually limit the family’s social life.

**Family Stress**

Stress in a family with a resistant eater can take on many shapes. One stressor may be that the extended family members struggle with the issues that the family are having. They may give unwarranted advice or make unkind statements questioning the parenting skills due to the resistant eating behaviors. Some families that have meddling extended families, limit their contact. Another stressor may be that these families eat in shifts. The children are fed one meal, and another meal is prepared for the adults or the mother eats the same meal as the child and makes a second meal for the father. Most of these families talked about having scheduled but separate meals. Only a few (2/7) families actually sat down for the evening meal as a family. Jesse’s mother stated that eating as a family is hard.

A third stressor is that the communication between the child and the parent can be strained because providing a healthy meal is the heart the nurturing mother. If she feels she can’t do that, then there could be feelings of guilt. Most of the mothers (5/7) interviewed mention the guilt they feel, somehow feeling that their child’s resistant eating behaviors was a result of something they did or did not do. One mother stated that she was responsible for his poor eating habits because she was a new mother and she made a lot of mistakes. Another mother stated that
when her son was 18 months he was eating regular foods and then they made a major move and where the culture was somewhat different from middle America and as a result, she gave him meat and rice for his meals. She mentioned that her husband also believes that if she would have given him more variety he would not have these resistant eating behaviors. Another mother puts the fault on a difficult pregnancy and early delivery after the adoption of the child. She feels that if she didn’t have the health concerns she had shortly after her adopted child arrived, that she would not have these behaviors. Mothers’ expressed a great deal of anxiety and tension when their child exhibited resistant eating behaviors and according to Timimi et al., 1997; Crist and Napier-Phillips, 2001, these mothers usually have a low confidence ability in their parenting skills and abilities to manage their child’s behaviors. For most families, difficulty in parent-child communications may often be met with resistance and conflict and as a result studies suggest that parents are less likely to communicate with their resistant eater, have less physical interactions and less involvement of their child’s life (Timimi et al., 1997; Nicholls and Bryant-Waugh, 2009). This study was not consistent with those findings. In fact, while the parents are met with resistance and conflict due to their child’s challenging mealtime behaviors, they appeared to have close positive relationships with them and were able to read their body language to anticipate probable tantrums. Parents stated that they are stern but they keep a calm quiet voice and if necessary they will pick up the child and leave the area. Parent-child communication can also be met with conflict and resistance when centered around feeding and eating behaviors (Nicholls and Bryant-Waugh, 2009). Communication can break down when the child is begging, screaming or crying about not wanting to eat a non-preferred food. Mothers’ report that the fathers are less tolerant, often cajoling the child to “take a bite, I did”, or catering to the needs of the child and bringing them a preferred food to replace the non-preferred food. This lack of communication between the two parents could create conflict and disagreements. Nicholls et al., (2001) and Timimi et al., (1997) indicate that resistant eating behaviors impact the family and can become a major family crisis. Often the child is viewed to be manipulative and the parents may feel resentment or doubt their ability to parent. This study also found this to be true. As most mothers (4/7) admitted that their husbands’ catered to the child and provided them with a snack or a preferred food to replace the non-preferred food.
Stress is not just for the parents, as other family members may also experience stress as well. Jacobi et al., 2000 and Werle et al., 1998 point out that those children who chronically refuse foods tend to create family stress as the parents try to appease the child’s resistant eating behaviors. Siblings of these resistant eaters observe the concessions that are made for the ASD child and they too try to ‘get away with it’ also. As Jesse’s mother stated “I think that the girls also pick up from his behavior too. The girls think if Jesse can do it why not me…so they kind of pick up similar behaviors.” Higgins et al. 2005 stated that disruptive antisocial behaviors such as tantrums, rigidity in routines and obsessive compulsive behaviors can erode the parent’s self-confidence and increase their feelings of failure. Jesse’s mother spoke about her feeling of failure when she is unable to feed her son a healthy and balanced meal and stated “It’s very hard. So…family meal time is hard.” Noah’s mother expressed that; “It is a huge concern. It’s extremely stressful” While Molly’s mother stated that “I feel bad for Molly’s sister because … I do that to her, where I’m serving them what Molly likes…. buying for Molly and not making the sister things that she likes too.” So to compensate for the sister, Molly’s mother has promised to make her the foods she desires more often. While this may decrease the guilt feelings, it increases the work load, unless her mother makes the same meal for Molly’s sister, father and self.

Implication for practice

As an occupational therapist, it is important to thoroughly examine the child’s resistant eating behaviors, the strategies that are used to increase eating, and the effect of this problem on the family as observed in the participants. Resistant eating behaviors cause huge concerns for these parents. These parents may have additional stresses, guilt and hold themselves responsible for the child’s resistant eating behaviors. In addition they may experience low confidence in their ability to parent. As therapists, we need to talk to the parents, discover what they do to increase the child’s food repertoire, how do they make compromises with the child and what social issues are most stressing. Therapists need to have a good understanding of what is going on in the home and try to learn how we can support and encourage these parents, guide them and provide them with ‘just the right’ amount of home activities to help but not to burden. Suggestions and home programs can work but this is something that needs to be tailored to the individual family because until you sit down and talk with the parents and begin to understand the stressors they have on a daily basis plus any additional guilt or responsibility these mothers place on themselves, you as a
therapist do not have the full picture. As an outsider, it is easy to say, these parents need to do what is best for the child, but as a therapist we also must be able to step back and trust that the parents are doing the best what is best for their family under these difficult situations. With that in mind, as therapist, we need to teach and lead gently.

Limitations

There are several limitations that need to be recognized from this study. The first limitation is the sample size. The sample was gleaned from a suburb of a central Ohio city. This sample may not be representative of the ASD population. Another limitation was that some participants (5/7) limited their food selections to less than 15 foods while the other two participants had a little more variety with preferred foods between 20 -30 in number. The sample size was smaller than proposed. The second limitation of this study was the interview process. It was difficult to interview the caregiver free of distractions and observe the child eating during the same session.

Recommendations for future research

Future studies should include a larger sample size with a more diverse population. Also it is suggested that the interview/observation be broken into two sessions, one for the interview when the child is not there and one for the observation. This was done for one family due to recorder difficulties and the mother was not distracted by the child and could talk freely without interruptions. Another suggestion is to delve more into the family issues and parents’ feeling to gain a better understanding of the family dynamics and the stressor of raising an ASD child with resistant eating behaviors.

Conclusions:

In conclusion, this study provided information about the stressors and strategies that these families deal with on a daily basis. It provided information and possible explanations of the behaviors and rituals that are so strongly adhered to by resistant eater and what kind of compromises these families make to get through the day. However, this study mainly provided insight and increased empathy for the parents of a child with resistant eating behaviors. Their individual stories seem to have those common bonds that may provide ideas for future therapies.
to give assistance to these families and to possibly provide beneficial suggestions that they can use to improve their lives and the lives of their children. It would be interesting to see if these common themes and parent attitudes ring true in a larger more diverse sample.
Bibliography


Lockner, D. W. PhD, RD., Crowe, T.K. PhD., Skipper, B. J. PhD., Dietary Intake and Parents’ Perception of Mealtime Behaviors in Preschool-Age Children with Autism Spectrum Disorder and in Typically Developing Children.


Appendix A

Prescreener
Please complete this nutrition questionnaire and if you have any questions don’t hesitate to contact Carolyn Hall, OTR/L at (614) 284-8458.

Child’s Name ___________________________ Date of Birth ___________________________

**Dietary History/Information:**

1) Was your child breast or bottle-fed?   Yes           No
2) If breastfed, for how long? ________________

3) If bottle-fed, please name the formula (with or without iron): __________________________

4) Is your child currently taking or have ever taken any vitamin or mineral supplements?   Yes   No
   o If yes, please provide brand name and duration: __________________________

5) Does your child like to eat with utensils?   Yes           No
   o If yes, which ones?

6) Does your child sit with the family through a meal at home?   Yes           No
   o Is this different when in a restaurant?   Yes           No
   o If yes, please explain.

7) Does your child seem to have problems chewing any certain foods or textures?   Yes           No
   o If yes, please explain.

8) Approximately how many foods does your child prefer?
9) Are there any certain foods or food groups that your child refuses to eat? Yes No
   - If yes, please list foods and/or food group(s) (grain, fruit, vegetable, meat, dairy) and explain any associated behaviors such as tantrums, etc if applicable.

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<th>Food/ Food Group</th>
<th>Associated Behaviors</th>
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**Pertinent Medical Information:**

10) Does your child have a diagnosis of Autism Spectrum Disorder Yes No
    - Autism
    - PDD
    - PDD–NOS
    - Asperger’s Syndrome

11) Does your child have any other diagnosis? Yes No

12) Is your child on any medicines? Yes No
   - If so what__________________________

13) Does your child have any known food allergies? Yes No
14) Does your child have any known food intolerances such as lactose or gluten?  Yes  No
   o  If yes, please list and explain symptoms (flatulence, cramping, etc).

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<th>Intolerance</th>
<th>Resulting Symptoms</th>
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15) Does your child have any chronic gastrointestinal issues such as Diarrhea, Constipation, Nausea, Vomiting, etc?  Yes  No
   o  If yes, please list all that apply, rank severity (mild, moderate, severe), and duration (how long has this been happening? Two weeks, three months, etc).

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<th>GI (gastrointestinal) Issue</th>
<th>Severity</th>
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Diet and/or Biomedical Therapy Information:

16) Is your child currently taking or have ever taken any dietary/herbal supplements (such as fish oil, probiotics, etc.)?  
   Yes  No  
   - If yes, please list brand name, product, and daily dosage.

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<tr>
<th>Brand Name  (i.e. Nature Way)</th>
<th>Product  (i.e. Fish Oil)</th>
<th>Dosage  (i.e. 400 mg/day)</th>
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17) Is your child currently or have they ever been on any special diet?  
   Yes  No  
   - If yes, please circle all that apply and provide the following details.
     - Gluten Free Casein Free Diet
     - Specific Carbohydrate Diet
     - Feingold Diet
     - Other _____________________
   - Reason for trying:
     - Did it seem to work, that is, did it improve what is was intended to improve (i.e. language, and/or behavior, etc)?  If yes, please explain:
     - How long has he/she been on the diet?

18) Is your child currently involved in or has ever been involved in any other therapies?  
   Yes  No
If yes, please list all that apply (chelation, HBOT, chiropractic, Energy Medicine, etc), whether or not it seemed to work (did it do as intended?), and the duration of each.

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<tr>
<th>Therapy</th>
<th>Did it Work? How (language, eye contact, etc)</th>
<th>Duration</th>
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Thank you for your time and again, I look forward to meeting you and your family.
Appendix B

Three-Day Food Journal
Please complete the following three day diet record before your appointment/interview. This provides an overall nutrition assessment of your child. If possible, please provide three consecutive days consisting of two weekdays and one weekend day. For example, Thursday, Friday and Saturday or Sunday, Monday and Tuesday. Any questions, please call Carolyn Hall at 614-284-8458.

**Day 1**

Name:___________________ Date and weekday:____________________

<table>
<thead>
<tr>
<th>Time</th>
<th>Food/Liquid</th>
<th>Amount <em>Eaten</em> (ounces, tbs, cup, etc)</th>
<th>Preparation (baked, fried, etc)</th>
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Day 2

Name: ___________________ Date and Weekday: __________________

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<th>Time</th>
<th>Food/Liquid</th>
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<th>Preparation (baked, fried, etc)</th>
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# Day 3

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<th>Food/Liquid</th>
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<th>Preparation (baked, fried, etc)</th>
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Appendix C

Interview
General information about the child’s meal time and routines:

Research question #2. What commonalities and idiosyncratic behaviors are observed in their children at mealtimes?

1. Tell me about meal time?
   a. Describe a typical meal.
   b. Do you have a scheduled mealtime?
   c. Does your child graze throughout the day?
   d. How long does your child take to eat a meal?
   e. Where do you and your child eat your dinner? At the table or in front of the television?
   f. Does your child sit down to eat?
   g. Does your family sit together for a meal?
   h. What does your child sit in/on when he/she eats?
   i. Does your child remain seated during the meal?
   j. How do you know if your child is hungry or full?

2. Tell me about your child’s routines around meal time?
   a. Does the food have to be prepared a specific way?
   b. Does the food need to be served in a specific way?
   c. Does packaging affect what they eat?
   d. Does your child have a specific plate, cup and utensils they must use for every meal?
   e. What happens if one food touches another?
3. Tell me about the foods your child prefers
   a. What kind of foods does your child eat?
   b. What kind of textures does your child prefer? (1. Pureed – applesauce, pudding, baby foods 2. Mashed lumpy - mashed potatoes soft fruits 3. Ground - ground meats, scrambled eggs, cottage cheese, toasted bread, crackers 4. Chopped foods that are chopped ¼ - ½ inch in size 5. Regular foods that are cut up or left whole)
   c. Does your child refuse to eat foods that require a lot of chewing?
   d. Does your child avoid certain food groups? If so, which ones?
   e. What happens if you give your child something he doesn’t like
      i. Can a non-preferred food be on the table
      ii. Can a non-preferred food be on the plate
   f. Do certain odors from cooking cause your child distress?

4. Does your child experience any physical pain or discomfort associated with meal time?
   a. Does your child’s stomach hurt after a meal?
   b. Does your child exhibit any pain, irritability or constant or sudden crying after a meal?
   c. Does your child want to lie down after a meal?
   d. Does your child have regular bowel movements?
   e. Does your child exhibit an increase in behaviors after eating?

Research Question #1. What mealtime behaviors are perceived by the families of ASD children with resistant eaters?
5. Does your child exhibit behaviors during meal time?
   a. What are these behaviors?
   b. Does the child cry, scream, tantrum, gag or vomit?
   c. What do you feel causes these behaviors?
   d. Does your child have more behaviors during mealtime as compared to another time of day?

6. When your child is exhibiting these behaviors how do you and your family responds to these outbursts?
   a. Do these behaviors disrupt your mealtime?
   b. Do you have rules and expectations for appropriate mealtime behavior?
   c. If so how do you manage inappropriate mealtime behaviors?

**Research Question #3. What are the experiences of families of children with ASD who have resistant eating behaviors?**

7. Tell me about what happens when you go out to eat with your child
   a. Do you and your family go to outings that include a meal?
   b. Do you bring your child preferred food or do you order food there?
   c. Does going to family centered restaurants diminish the behaviors?
   d. What do you do to try to avoid a behavior outburst when in public?
   e. What happens when your child has a behavior outburst in public?

8. How do you feel your child’s restricted eating behaviors impact your family?
a. Does your family avoid these social situations?

b. What tricks have you learned that you could share with others that allow your family to eat out?

9. Tell me about what meal time looks like at a family get together?

   a. What or how do your relatives respond when your child does not eat?
   
   b. As a result of your extended family’s comments/concerns do you avoid these family get togethers?

Research Questions  #3. Do parents feel that the family’s eating habits are affected by the child's eating patterns or vise versa? If so, in what way?

10. Do your child’s resistant eating habits reflect you or your husband’s eating patterns?

    a. Does your child’s pickiness dictate what you serve
    
    b. Do family food preferences influence your child’s food choices?
    
    c. Is anyone else in your immediate family having this same type of eating behaviors?
    
    d. Overall, with the exception of your child, do you feel your family eats a wide variety of foods and textures?

11. History of your child.

    a. Was your child breast or bottle fed?
    
    b. Have they been on special diets?
    
    c. If so which one and how did they do on it?
d. When you made the transition to baby foods, when did you notice the eating issues?

e. Did or does your child have allergies?

f. Did your child have colic as a baby?

g. Did your child experience any painful or traumatic experiences associated with eating?