

ASSESSMENT OF FOOD RELATED BEHAVIOR AMONG CHILDREN
DIAGNOSED WITH AUTISM AND THE EMOTIONAL IMPACT OF PARENTS

By

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ABSTRACT

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Having a child on the Autism spectrum can present a variety of challenges for parents. Many children diagnosed on the Autism spectrum experience communication and social struggles; as well as sensory related difficulties. Some children's inappropriate behaviors are related to specific events, such as mealtime which can be particularly challenging. This study examines the difficulties parents experience during mealtime with their children on the Autism Spectrum and the emotional affect mealtime behaviors have on the parent. In addition, the purpose of this study was to determine whether parents desire additional information that would assist them during mealtimes. Twenty-four participants participated in completing a survey which included various questions surrounding mealtime behaviors and routines, as well as questions pertaining to the emotional effect on the parents. Results revealed verbal protest as the most prominent behavior displayed during mealtime. Additionally, results revealed that although parents experience a high level of stress and frustration during mealtime they do not wish to receive supportive information.

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This is dedicated to my whole family, for their continuing love and support; but more specifically to my parents. I would not be where I am at today without them. Because of them I was able to climb the highest mountain that I ever dreamed I could climb. Because of them I defeated my fears took the bull by the horns. Through thick and thin, you are always there for me, so thank you Mom and Dad from the bottom of my heart.

I would also like to dedicate this to my best friend Nicky, your love is priceless. Lastly, I would like to thank David Ellered and Eric Van Duzer for continuing to support me through this journey in life; I couldn't have done it without you two.

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LITERATURE REVIEW

Introduction and Overview

Children with autism and their families often require outside behavioral resources to support and encourage a positive change in mealtime behaviors due to the high degree of behavioral issues that can persist for the remainder of their lives. It is crucial for parents, who may have exhausted their own efforts to supply their children with the best nutritional diet plan, to have supportive behavioral strategies and interventions. More importantly, effects of mealtime behaviors on children and the family can be overwhelming and may cause long term complications for the child and the parent if intervention strategies are not implemented early. Thus, the aim of this literature review is to investigate behavioral difficulties parents experience around mealtime involving their children diagnosed on the autism spectrum; in addition to investigating the effects having a child on the spectrum has on the parent during mealtime and their desire for more information.

This literature review will begin with the history of autism, followed by a definition/diagnoses, characteristics, prevalence/causes, and treatment. The review then moves onto defining behavior and functional behavior assessments (FBA). Next, the literature review will discuss difficulties surrounding mealtime and nutrition, and will end with a discussion of family variables and dynamics, as well as intervention strategies.

History of Autism

Prior to the early 20th century many individuals were living with autistic type characteristics before it was known as autism (Scheuermann & Webber, 2002).

Numerous stories were told describing individuals with characteristics of the disorder; however, it was not until 1943 that Leo Kanner identified the syndrome as “autism.”

Kanner came to this discovery by examining eleven children with what he called “early infantile autism,” defining autism as a distinct syndrome instead of previous conceptions in which children were thought to be “feeble-minded, retarded, idiotic, moronic, or schizoid.” (Kanner, 1943; Miller, 2003, para. 3).

Kanner (1943) defined the main characteristics of autism as communication deficits, need for a likeness, and an inability to relate to others among the eleven children studied. Kanner’s discovery created a building block for further exploration on autism leading to various discoveries of finer classifications with which to describe autism. These classifications included High Functioning Autism, Atypical Autism, Kanner’s autism, Childhood Disintegrative Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) (American Psychiatric Association [APA], 2013). Today, the Diagnostic Statistical Manual for Mental Disorders (DSM-V) includes criteria an individual must display to be diagnosed with autism.

Autism: Definition and Diagnosis

Autism is a neurodevelopmental disorder that falls under Autism Spectrum Disorder (ASD) as presented in the Diagnostic and Statistical Manual of Mental Disorders (APA, 2013). The DSM-V expansively defines autism as demonstrating “deficits in areas such as social interaction and communication, in addition to showing restricted, repetitive patterns of behavior, interests, or activities” (APA, 2013, p. 31). These symptoms appear in early childhood and effect the functioning of each individual differently depending on surrounding environments and unique characteristics the child displays (APA, 2013). Indicators appear at different levels of functioning according to the child’s developmental level, chronological age, in addition to the severity of the disorder (APA, 2013). Additionally, individuals diagnosed with autism spectrum disorder frequently suffer from an intellectual disability (APA, 2013).

Signs of autism like characteristics typically appear between 12-24 months of age, however a child may show symptoms of the disease much earlier depending on the severity of their development (APA, 2013). Multiple sources of information such as assessments, self-report (if possible), clinical observations, and care giver/educator reports help the diagnosis process (APA, 2013). According to Badalyan’s 2011 study, the average age of diagnosis for children with autism is 3.1 years of age.

Additionally, approximately 24% to 30% of children diagnosed with autism can clearly articulate words, repeat the ABC’s, and count numbers aloud. However, in certain cases, children will regress, losing some or all of their speech, in addition to the loss of

eye contact and social skills in some cases (Johnson & Myers, 2007). This regression can be sudden or gradual and typically happens during the ages of 15-24 months, and occurs quite frequently with children who have already been diagnosed (Johnson & Myers, 2007).

In several cases, children may not receive a diagnosis of autism until much later in life (Center for Disease Control [CDC], 2014). When undiagnosed, autism can dramatically impact the individual in terms of their daily functioning including their social, cognitive and emotional development. In turn, parents tend to feel the impact as well; absorbing the reality of the situation and prolonging the/ process of diagnosis, cheating the child out of obtaining new skills and leaving the family in continued distress. When diagnosed, differing characteristics appear in every individual, with the severity of each diagnosis varying significantly (Johnson & Myers, 2007). The specific characteristics attributed to autism are described in the next section.

Characteristics of Autism

Social interactions such as developing, maintaining and understanding relationships do not come easy for individuals diagnosed with autism. These abilities appear at different stages of life, leaving it difficult for parents to determine whether their child is developing on a typical level. For example, some children with autism who exhibit social reciprocity deficits often show the signs early in life, however parents might struggle to identify and understand any delay their child might be demonstrating until later (Johnson & Myers, 2007).

Children who have autism also exhibit an inherent inability to read and comprehend emotions, experiences, and social intentions of others (Batshaw, 2007). Difficulties understanding non-verbal messages such as facial expressions, and bodily gestures as well as failure to maintain eye contact or engage in conversations are often apparent early on (Batshaw, 2007). Furthermore, children have a hard time grasping the concept of imaginary play and struggle with building and maintaining friendships due to their abnormal repetitive behavior and interests, often responding inappropriately (APA, 2013). These bizarre and abnormal behaviors will often attract peers' attention, causing judgment, and in turn dissolves relationships or prevents any new relationships from forming.

Communication plays a huge part in daily living and is one of the most common deficits in children diagnosed on the spectrum. Communication with others involves two components, form and function. Form refers to various behaviors used to demonstrate a child's need or wants, such as hand leading, gestures, verbal, crying, body movements, and aggression (Scheuermann & Webber, 2002). This simply involves anything that a child does to attract someone's attention, causing a reaction or response. Often a child with Autism will be taught, or learn their own means of communication that best fits their needs. The other component of language, function, refers to the intent the child has for communication. For example the child might use communication to request, protest, play, among several other reasons in order to gain one's attention (Scheuermann & Webber, 2002). These two components of language play a major role when assessing a child to determine reasons why a child may be behaving in a certain way.

Most children with autism communicate in some method that is understandable to them and others, however often times their language is far from developed. In fact, research shows communication is typically the first area of concern that the parent identifies (Batshaw, 2007; Scheuermann & Webber, 2002). Furthermore, a child may show trouble with receptive and expressive language, an inability to maintain a back and forth conversation. A child may also regularly repeat part of what someone is communicating, often known as echolalia (Johnson & Myers, 2007). For example, a child may be asked “Would you like to go outside?” and the child will respond with “Go outside” or “outside” instead of answering the primary question. Additionally, many children on the spectrum may struggle or fail to maintain an appropriate conversation; using abnormal vocals and misusing pronouns, while showing little to no emotion or attention when communicating with other adults or peers (APA, 2013; Johnson & Myers, 2007).

In addition, children with autism regularly experience mild to extreme sensitivity to textures, smells, and sounds, as well as exhibit extreme attention to inappropriate items, and, at times, show repetitive unusual behaviors or interests (APA, 2013). Some children with autism become extremely dependent on routines and may become sensitive to any immediate change in their surroundings (APA, 2013). If a child’s common routines or surroundings are suddenly altered, problem behaviors often occur (APA, 2013). Additionally, children diagnosed with autism may not play with their toys in the intended manner, but instead display divergent behaviors such as lining blocks in a row rather than stacking them or turning the wheels on a toy repeatedly instead of pretending

to drive the toy around. Furthermore, pretend play becomes a matter of rote learning rather than occurring naturally in certain stages of development (Batshaw, 2007).

“Pacing, spinning, running in circles, drumming, flipping light switches, rocking, hand waving, arm flapping, and toe walking are common stereotype repetitive movements that may occur” (Batshaw, 2007, p. 329). Interruption to any of these repetitive type behaviors may lead to a variety of unpredictable and inappropriate behaviors that can often be difficult to manage. Additionally, complications surrounding social interactions, communication and repetitive behaviors can occur at different times in a child’s life, and differ according to each individual; therefore continuing research in determining possible causes and rates of prevalence is extremely important and will be discussed in the next section.

Prevalence and Causes

The number of children diagnosed on the autism spectrum has nearly doubled over the past 15 years. Information gathered from the Center for Disease Control (CDC) show that in the year 2000, 1 in 150 children were diagnosed with autism, and in 2008 the rate of prevalence increased to 1 in 88 children (CDC, 2014). Additionally, information released by the CDC in March 2014 show 1 in 68 children were diagnosed with Autism Spectrum Disorder (ASD) (CDC, 2014). Furthermore, research shows that in March of 2014 1 in 48 boys and 1 in 189 girls were diagnosed with autism, showing that boys are 5 times more likely to be diagnosed with autism than girls (Autism Speaks, 2014).

Although several possible causes of autism have been theorized, there is still no known cause to this mysterious disorder. However, a recent investigation conducted in 2013 led researchers to find a disruption in enzyme formation, called topoisomerases that could be a link to the recent growth of autism (Norton, 2013). King et al. (2013) revealed “the topoisomerases facilitate the expression of a large number of ASD candidate genes, including many that are long and that are thought to have large effects on ASD pathology in isolation.” (para. 6) However, the “mechanics” involving the topoisomerase link to autism remains unclear (King et al., 2013). Additionally, it is known that topoisomerases disrupts the neurodevelopment disorders such as autism; however there is no evidence to prove the link causes autism (Vokálova, Durdiaková & Ostatníková, 2015).

Additionally, researchers have evidence to support a claim that genes play a role in the cause of autism (CDC, 2014). Yet, researchers believe more than just genetics play a role in the cause of autism; due to the rapid increase in diagnosis over the years (CDC, 2014). However researchers have yet to determine the specific genetic influences that cause autism. Experts in the field are also certain that environmental factors influence autism (CDC, 2014; Norton, 2013). Furthermore, some believe gluten and casein may be a cause of autism, or at least have an effect, due to the many toxins that are released upon ingestion; however very little data has been found to support these claims as most studies conducted were small (Malone, Gratz, Delaney, & Hyman, 2005).

Researchers and scientists are continually addressing the possible underlying causes of autism, analyzing brain development, possible specific environmental factors, mutation/genetics; among exploration of other possibilities (National Institute of

Neurological Disorders and Stroke, 2009). With further development into the possible causes of autism; treatment plans will in turn become more effective and successful, which will be discussed in the next section.

Treatment

Various Evidence-based practices have been developed to support early behavioral intervention. The National Development Professional Center on Autism Spectrum Disorder has compiled a list of twenty-seven practices that have shown to be effective in supporting children on the spectrum when applied correctly (National Professional Development Center on Autism Spectrum Disorder [NPDC], 2016). Evidence-based practices allow the child to gain specialized support surrounding development; focusing on specific areas of deficits such as social skills, language abilities, motor aptitude, among other needs. Some of these practices include but are not limited to: Cognitive Behavioral Intervention (CBI), Discrete Trial Teaching (DTT), Parent Implemented Intervention (PII), and Antecedent-based Intervention (ABI), Picture Exchange Communication System (PECS), Pivotal Response Training (PRT) (National Professional Development Center on Autism Spectrum Disorder [NPDC], 2016).

In addition, there are various other treatments that help improve deficits in children with autism not listed on the National Development Center on Autism Spectrum Disorder, such as: “auditory training, vitamin therapy, anti-yeast therapy, facilitated communication, music therapy, occupational therapy, physical therapy, and sensory integration” (CDC, 2014, para. 6; Malone et al., 2005). Additionally, some

pharmaceuticals are shown to help individuals diagnosed with autism increase abilities in certain areas. Such medications help children regulate energy levels, improve focus, control obsessive-compulsive disorders (OCD), aggression, and improve symptoms around persistent and repetitive behaviors (CDC, 2014; Malone et al., 2005). Five different double-blind experiments and controlled studies, showed antipsychotics drugs such as haloperidol and risperidone to effectively reduce autism like symptoms (Malone et al., 2005). Although research shows medicine has assisted some children with autism; it is not effective for all children. Therefore, it is important to understand each individual separately to determine a treatment plan that best suit their needs. When determining the necessary treatment, an analysis of behavior is important to look at and therefore will be discussed in the next section of the literature review.

Behavior Defined

Challenging behaviors occur daily with many children and their families; however, children diagnosed on the autism spectrum often struggle in a greater fashion. Children with autism might lash out with challenging behaviors at unknown times, and to a severe degree. Therefore, specialists in the field of special education focus intensively on the underlying variables surrounding challenging behaviors to both help and understand each struggling individual.

Behavior involves a “function,” defined as the reason and purpose of a child’s conduct. For example, “why is the child continually throwing his spoon and food across the table during mealtimes?” Or “why is the child screaming at the top of his lungs while

hitting himself during mealtime?” Determining the function of a behavior is a crucial and necessary element needed to implement proper behavioral strategies. Children may display behaviors when trying to gain access to a preferred item, when seeking attention, or to escape a demand/task (Trumpet Behavioral Health, 2014). Studies reveal that most challenging behaviors observed around mealtime are displayed through the function of escape (Addison et al., 2012; Najdowski et al., 2008). Additionally, a child may become over stimulated by certain sensory related events and experiences that lead to challenging behaviors (Trumpet Behavioral Health, 2014). To determine the function of any behavior, a behavioral analyst will often use what is called a “functional behavioral assessment” (FBA) to analyze the ins and outs of behavior (O’Neill et al., 1997).

FBA’s help gain a clear understanding of the difficulties surrounding behavior and possible factors such as; environmental, social, affective, cognitive, or behavioral that may be inducing the specific behavior (Scheuermann & Webber, 2002). Najdowski et al. (2008) established the importance of these functional assessments and the impact they have on determining treatment plans for children with food refusal and/or food selectivity issues. Additionally, a study conducted by Sharp and Jaquess (2009) demonstrated the impact, by showing how treatments are more effective when behaviorists evaluate the motive behind disruptive behaviors, showing success from one variable to the next.

Specific principles help determine a plan for treatment when conducting a functional behavioral assessment, these include determining: (1) “behavior is related to specific antecedent and consequences in the immediate environment,” (2) “behavior may

be affected by conditions other than immediate antecedents and consequences,” (3) “behavior may be related to biological causes,” (4) “challenging behaviors may serve a function for the child” (5) “challenging behavior may be the result of a skill deficit” (Scheuermann & Webber, 2002, p. 62-63). As part of a functional behavioral assessment, behavior specialist use a “ABC” (Antecedent, Behavior, and Consequence) technique as a mode of tracking a child’s behavior and to aid in the construction of intervention.

Analyzing the 3 “ABC” dimensions of behavior allows a behaviorist to gain a better understanding of each event and elements related to the particular behavior, that helps construct behavioral intervention plans. This tracking occurs prior to intervention, as well as during the intervention process to ensure the child receives the proper treatment, and to make sure the intervention strategies are working. The antecedent (A) of a behavior happens prior to the behavior, whereas the behavior (B) involves an objective description of the inappropriate behavior, and consequence (C) occurs following the antecedent and behavior; describing exactly what happened after the target behavior occurred.

Analyzing the variables surrounding the antecedent may increase the effectiveness of intervention dramatically (Sharp, Harker, & Jaquess, 2010). Additionally, during the intervention process, data surrounding behaviors are kept periodically and daily to ensure that the intervention process is working. If data shows little to no progress over a period of time; re-evaluation and adjustments to the treatment plan are made. All in all understanding the dimensions of a child’s conduct can be

particularly valuable concerning any situation; including issues surrounding difficult mealtime routines.

Mealtime/Nutrition and Behavior

Many children on the Autism Spectrum experience a difficult time related to eating, often displaying food selectivity issues pertaining to food and mealtime. It is important to ensure proper nutritional value to maintain healthy minds and bodies; unfortunately, this does not come easy for all children. Many children struggle around mealtime; however children diagnosed with autism struggle to a much higher degree with 30-80% of children with autism suffering from food related behaviors, as opposed to 45% of their typically developing peers (Binnendyk & Lucyshyn, 2009). According to a study conducted in 2001, 57% of children exhibited food selectivity by texture or type and 87% of children showed low acceptance of food (Ahearn, Castine, Nault, & Green, 2001). Additionally, children diagnosed with autism experience more feeding problems and behaviors than any other children, with 72% of children eating a small selection of foods (Schreck, Williams, & Smith, 2004).

A study conducted by Cornish (1998) showed 100% of the parents interviewed who have children on the autism spectrum, reported having a struggle around the introduction of new food items. Another study conducted by Cornish (1998) involved 17 participants diagnosed with autism ranging in age from 3 years 6 months to 9 years 9 months. The aim of the study was to investigate selectivity nutrition deficits and abnormal feeding patterns among children (Cornish, 1998). Cornish found 59% of the

children ate fewer than 20 different foods, and 54% of the children were living with nutritional deficits (Cornish, 1998).

In an additional study, Cornish (2002) investigated 37 participants diagnosed with autism, 31 boys and 6 girls ranging in age from 3 years to 6 years to determine if restrictive diets affected children with autism and to determine their preference of food. Cornish found between 32% and 50% of children had deficits in their nutrition and 89% exhibited food selectivity (Cornish, 2002). Cornish also investigated possible differences between individuals placed on a restrictive gluten-free or casein-free diet versus those who remained on an open diet (Cornish, 2002). The results of his study revealed no significant differences (Cornish, 2002).

Abnormal behavior related to food is a growing concern for children with autism. Research shows children exhibit various degrees of distaste for particular textures while appearing to have a liking for other textures, whether the liking is for food or unusual and inedible objects (Martins, Young, & Robson, 2008). Additionally, children diagnosed with autism fixate on a certain brand or particular color of food showing selective preferences to commercial brands of food and textures (Levin & Carr, 2001). Furthermore, despite efforts to conceal an alternative brand of favored food in different packaging, children with autism will generally experience inappropriate behavior, protesting the item presented to them (Martins, Young, & Robson, 2008). Another factor influencing inappropriate behaviors around mealtime might be the way the food is presented to the child, such as the type of plate or utensil used, or the way the food is placed on the plate. This makes mealtime more difficult and stressful for families due to

the added effort and energy expended to prevent possible behaviors around the acceptance of food items.

Ahearn et al.'s 2001 study examined food acceptance among children with developmental disabilities. Research revealed low levels of acceptance among the children when presented with certain food items (Ahearn et al., 2001). Ahearn et al. (2001) also discovered food refusal and challenging behaviors occurred frequently together among the 30 children studied. Four of the participants in the study displayed zero acceptances of food items offered to them, confirming the struggle around mealtime behavior and the need to find strategies to increase the acceptance of food items (Ahearn et al., 2001). Although research shows the extent to which children struggle around food; research also shows the extent to which parents and families suffer, which will be discussed next.

Family

The initial shock of learning your child has been diagnosed with autism can be overwhelming; layered with feelings of disbelief and anger. Parents experience an immense amount of worry and panic the moment they recognize a possible developmental delay in their child's functioning. For example, a parent in a study conducted by Zhou & Yi (2014) mentioned, "I became very anxious and irritable after obtaining the diagnosis; I had to do something to make me feel better" (p. 72). Additionally, the resulting stress from having a child diagnosed with autism can sometimes make parenting nearly unmanageable, leaving parents upset and in denial;

pondering what role they may have played that caused their child to have autism (Batshaw, 2007).

Mild to extreme behavioral problems can be particularly hard for parents who have a child on the autism spectrum; which lead to a plethora of emotional consequences such as depression and anxiety. A study conducted by Hurdock (2013) showed high levels of stress among 69 parents when their child with autism engaged in challenging behaviors. The strong link between parental stress and a child's behaviors can lead to varying emotional and physical ailments (Hastings, 2002). Furthermore, in a study conducted by Zhou and Yi (2014), parents reported feeling as if their emotional levels of distress had a substantial impact on the way their child behaved. They also reported feelings of "anxiety, hopelessness, anger, and powerlessness" after discovering their child has autism (Zhou & Yi, 2014, p. 75). In fact many times the child's behaviors influenced the parents anxiety levels with one parent reporting: "My emotions enter a vicious cycle: his retrogressing makes me stressed and my bad mood makes him even worse" (Zhou & Yi, 2014, p. 75). With limited time and resources in combination with immense emotional pressure, parents become easily distraught in regards to how to give supportive and effective care to their children. Therefore, parents will turn to outside agencies in effort to seek effective early intervention for their child on the spectrum.

Intervention

Various studies have shown the tremendous impact behavioral therapists have on children with autism through implementation of appropriate intervention plans (Hastings

& Brown, 2000). Intervention plans not only improve a child's skill set, challenging behaviors, or other concerns; they also improve the emotional well-being of the parents (Hastings & Beck, 2004). To meet the needs of family members with compassion and understanding, professionals must consider the dynamics of individual families, their needs, characteristics, strengths, values, resources, and their particular stage within the family life cycle (Berkell, 1992). The process of determining an intervention plan to implement can be extremely difficult on the parents or caregiver; leading to a variety of issues the parent may raise. For example, in a study conducted by Herbert (2014), twenty three parents discussed their rationale behind their decision making for 19 children diagnosed on the autism spectrum. At the time of initial diagnosis, parents were presented with two approaches; a behavioral approach Applied Behavioral Analysis (ABA) and a developmental individualized relationship-based (DIR) method (Hebert, 2014). The findings revealed three main parental concerns surrounded intervention; child attributes, parental attributes, and assessment of the intervention plan (Herbert, 2014). Although these concerns may be prominent; intervention strategies such as escape extinction (EE) and differential reinforcement (DR) allow families to reach a level of security regarding their child's challenging needs when given the opportunity.

Many researchers have confirmed that escape extinction increases food acceptance among children with selective eating (Ahearn et al., 2001; Allison, et al., 2012; Anderson & McMillan, 2001; Freeman & Piazza, 1998; Najdowski, Wallace, Doney, & Ghezzi, 2003). Escape extinction is an intervention strategy used in applied behavioral analysis (ABA) to treat behavioral issues. Negative reinforcement is the main

component of escape extinction and involves the removal of a particular stimulus upon a specific behavior or response from the child (Ledford & Gast, 2006). Essentially, a child is not allowed to escape the specific demand that was placed upon the child, such as eating a non-preferred food (Ledford & Gast, 2006).

As part of an intervention plan, escape extinction has allowed many research specialists to increase food acceptance among children with issues around eating. For example, Ahearn (2003) increased vegetable consumption for a 14-yr-old boy with autism from 0% to 100%. Additionally, Anderson and McMillian (2001) improved the consumption of fruit with a 5-yr-old boy from 50% to a 100% over 37 sessions. Furthermore, Freeman & Piazza (1998) conducted a study across twelve weeks that involved 2-4 meals a day and found an increase in consumption of food for a 6-yr-old girl with autism from 0 grams consumed a day to 150 grams.

Likewise, differential reinforcement (DR) has proven to result in an increase in food acceptance among children diagnosed on the autism spectrum. Differential reinforcement, the opposite of EE, involves positive reinforcement when a positive behavior is displayed, and removal of reinforcement for unwanted actions (Ledford & Gast, 2006). Various researchers found that differential reinforcement provides a dramatic increase in food acceptance among children studied (Ahearn, 2002; Anderson & McMillian, 2001; Freeman & Piazza, 1998; Levin & Carr, 2001; Najdowski et al., 2003).

For example, Levin and Carr (2001) found an increase in consumption of non-preferred foods contingent on limited access and differential reinforcement. Additionally, Najdowski et al. (2001) conducted a study showing an increase in non-preferred food

consumption, with an increase from 0 to 62 bites across 79 sessions with a 5-yr-old boy diagnosed with autism. Furthermore, Ahearn (2002) increased the variety of foods consumed among four boys and two girls between the ages of 4 -11, two diagnosed with Pervasive Development Disorder-Not Otherwise Specified (PDD-NOS), and four with autism by using the strategy. He found an 80% increase in the acceptance of a variety of foods among all participants (Ahearn, 2002). Many studies have shown the combination of escape extinction and differential reinforcement to be positive among children who may have had previous medical problems or children who may have been reliant on feeding tubes (Ledford & Gast, 2006).

Summary

This literature review examined the research surrounding children diagnosed with autism who have difficulties and challenges related to mealtime that dramatically affect the parents' and child's emotional stability. Characteristics, prevalence and causes of autism were included, allowing the reader to gain a better understanding of the increase of autism and the ongoing trials and tribulations these children go through.

Due to the growing numbers of children diagnosed with autism, reducing challenging behaviors as well as increasing acceptance of non-preferred foods is essential. Therefore, the aim of this study considers strategies that will give parents and children the desired life they deserve.

METHODS

Participants

Upon Institutional Review Board (IRB) approval for the study, local agencies and a non-profit associated with Autism programming were contacted and asked to inform potential participants via social media of the study being conducted. A self-selected sample of twenty four Humboldt County parents who have children diagnosed on the autism spectrum were recruited to participate in this study during public Autism support events.

Materials

The survey consisted of fifteen questions that relate to issues and behaviors of parents and children during mealtime. Question response scales included yes/no, open ended, and likert scales. Questions on the survey addressed overall parent feelings during mealtime, addressing level of stress, anxiousness, frustration, and successfulness during mealtimes. Additionally, the frequencies of events that occur during mealtime such as food throwing, kicking, verbal protests, parent attention and parent energy during mealtimes were measured. Behavioral questions addressing how often parents reward or punish behaviors, ignore bad behaviors, or use certain cues to aid their child into trying new food were also examined. Other questions included asking whether the parent was a single parent, how many children they have, and whether or not they receive behavioral

services for their child with special needs. Lastly, two open ended questions were asked. The first question addressed whether parents want to learn more about behavioral strategies that could help improve mealtime; asking them to explain specifically what they would like to learn. While, the second question asked whether the family receives any behavioral services for their child and if so what areas do they focus on.

Procedure

The survey was available for voluntary participation at three local events in Humboldt County. The first event included a movie screening at Broadway Cinema in Eureka, California for families with children on the autism spectrum put on by a local organization named Families Advocating Autism Now (FANN). FANN also held the second event in Fortuna, California at Rohnert Park called Family Fun Day where families were invited to participate in activities such as roller skating, bouncy house, and face painting. Lastly, a local agency Starfish Hero held the third event in McKinleyville, California at Azalea hall that also provided families with an opportunity to play fun games and watch movies. For all events, a table was set up for participants to voluntarily participate at any time. Clipboards and pens were provided in addition to a lock box for participants to anonymously place their survey which took participants anywhere from 5 minutes to 10 minutes to complete. Responses on surveys included three demographic questions, two open ended responses, five yes no questions; as well as number scales where participants ranked from 1-5 for three questions and 1-7 for one. Data analysis included calculating average scores, such as the average total score of parents reporting

high levels of emotional distress, and the average score of how frequent mealtime behaviors occur; as well as calculations of descriptive information such as the proportion of parents who reported “Stress” as the prominent emotional feeling during mealtime versus the proportion of parents who reported feeling “Anxious”, or the proportion of participants who reported their child displaying verbal protests during mealtime, versus those parents who reported their child displaying kicking behaviors. Additionally, data was analyzed to investigate whether parents felt the need for additional behavioral strategies to help improve mealtime behaviors by calculating those parents who reported “yes” to the question asking “Do you want to learn more about mealtime behavioral strategies.

RESULTS

Mealtime Emotional Effect on Parents

Participants were asked to describe their level of feelings in regards to five different emotions. This involved ranking emotions on a semantic differential scale of how they feel in terms of; stressed to calm, anxious to peaceful, frustrated to satisfied, unsuccessful to successful, and worried about behavior to confident in good behavior. With a scale of 1-7 with 1 being the highest level stressed, anxious, frustrated, unsuccessful, and worried about behavior, and 7 being the lowest feeling of calm, peaceful, satisfied, successful, and confident in good behavior; with 4 representing a neutral feeling. Of the five emotional responses to mealtime, parents felt that stress was the most common emotion felt ($M = 4.38, SD = 1.73$) Worry around mealtime was ranked as the second highest emotion felt with their child ($M = 4.17 SD = 1.50$). The third highest level of negative emotion were feeling anxious around mealtime ($M=3.92, SD = 1.59$) (See Figure 1).

When parents were asked whether they perceive mealtime to be stressful 24 participants responded with “yes” (N = 15) reporting mealtime to be stressful and (N = 9) reported mealtime as not being stressful.

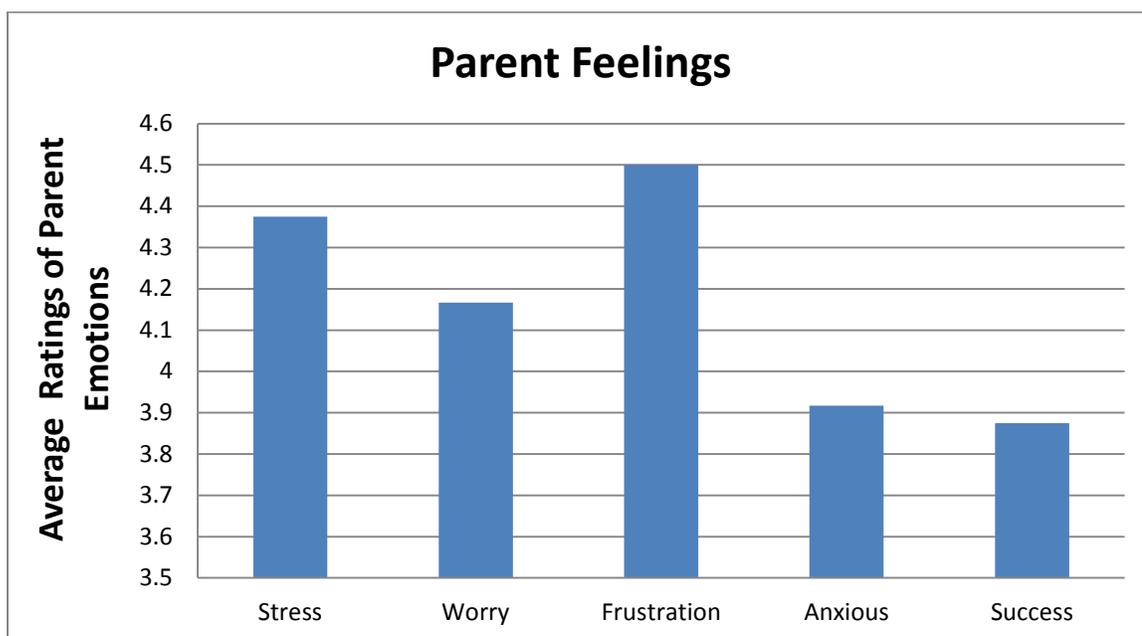


Figure 1. Average ratings of parent emotion surrounding mealtime using a 1-7 Likert Scale.

Mealtime Behavior

The survey then asked parents to rate the frequency of three different behaviors (kicking, throwing, and verbal protest) during mealtime on a scale of 1 to 5 with 1 being “never”, 2 “rarely”, 3 “sometimes”, 4 “often” and 5 being “always.” Analysis of these results indicated that verbal protesting happens more frequently than any other that behavior ($M = 2.41$, $SD = 1.26$). Kicking behavior was the second most frequent behavior ($M = 2.05$, $SD = 1.09$). The frequency of throwing behavior was reported as occurring the least during mealtime ($M = 1.636$, $SD = 1.049$).

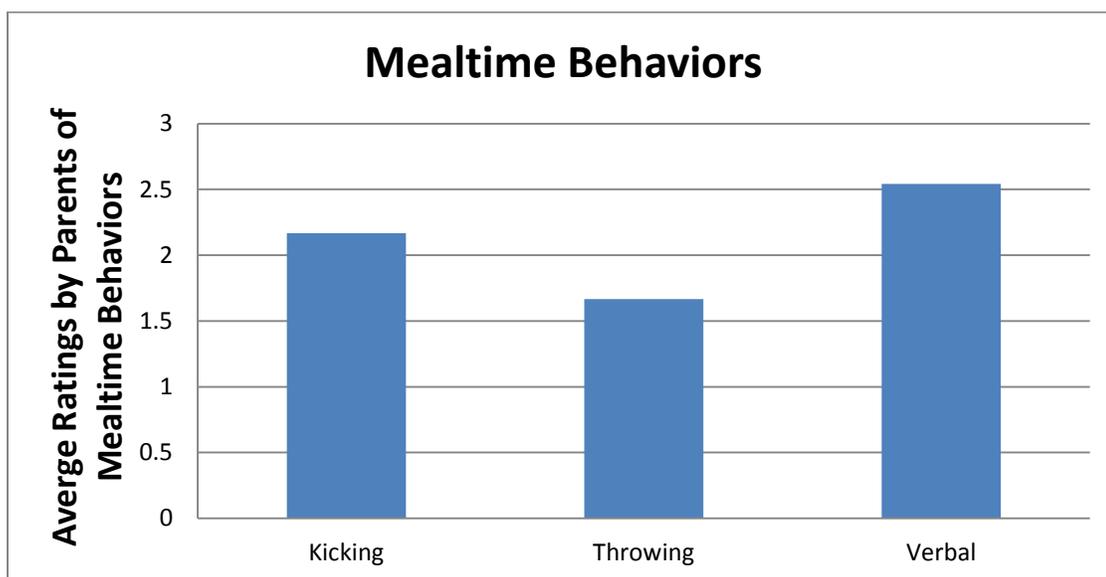


Figure 2. Average rating of mealtime behavior's using a 1-5 Likert Scale.

Parental Use of Behavioral Strategies

Using a Likert scale of Never to Always (1-5), participants were asked to report how frequently they used various behavior mitigation methods (verbal cues, positive or negative reinforcement and waiting) during mealtime with their child. The scale included the frequency of positive and negative reinforcement and use of verbal or non-verbal cues to guide their child, and the use of waiting out their child's unwanted behavior. Results showed parents reported verbal cues as strategy they used most frequent with their child to aide in reducing negative mealtime behavior ($M = 3.95$, $SD = 0.785$). Parents rated positive reinforcement as the second most common method used during mealtime ($M = 3.23$, $SD = 0.81$). According to the results, parents primarily encourage their child to have a successful mealtime by consistently providing verbal cues in addition to rewarding

some behaviors but not others. Additionally, parents reported the third most frequent tactic to reducing behaviors around mealtime is to wait out their child's undesired behavior ($M = 2.86$, $SD = 1.207$, see Figure 3).

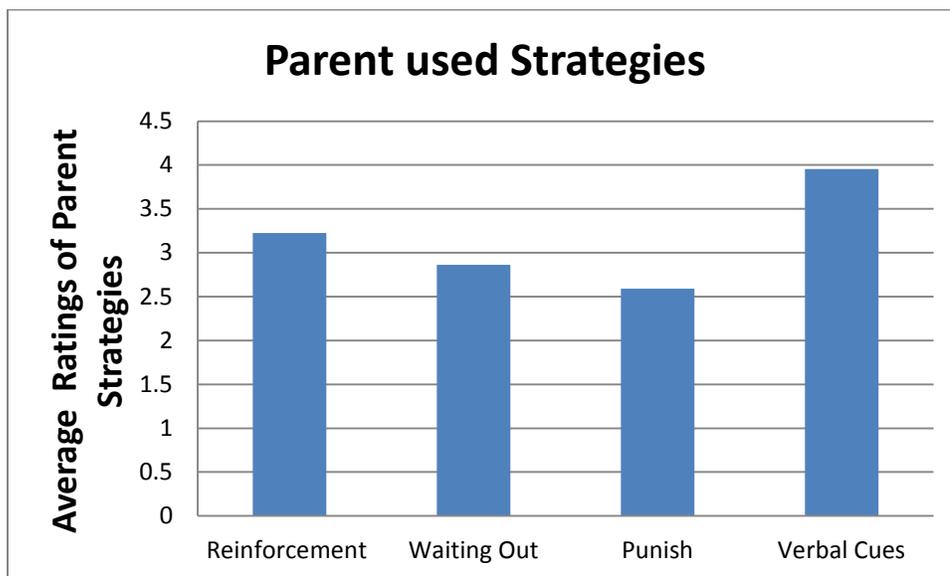


Figure 3. Average use of behavioral strategies used at mealtime by parents using a 1-5 Likert Scale.

Desire for More Mealtime Behavior Information

As reported above, when parents were asked whether they perceive mealtime to be stressful 24 participants responded with “yes” ($N = 15$) reporting mealtime to be stressful and ($N = 9$) reported mealtime as not being stressful. However, when parents were asked whether they wished to receive more information regarding behavioral strategies around mealtime, out of the 19 participants that responded to the question; the majority responded with “no” ($N = 12$), and 7 participants reported “yes” ($N = 7$).

Furthermore, when parents were questioned whether they currently receive behavioral services around mealtime 23 participants responded with a majority reporting “no” (N = 18), with very few reporting “yes” (N = 5).

Mealtime Routines/Practices

A likert scale of Never to Always (1-5) was used to ask what type of things parents and their child do during mealtimes. Parents reported the most frequently used parental behavior practiced at the dinner table was having their child sit down with them during mealtimes ($M = 4.23$, $SD = 0.81$). Parents reported letting their child decide what and how much they wish to eat as second most routine ($M = 3.68$, $SD = 1.13$); with introducing new foods for their child to try ranking closely behind ($M = 3.36$, $SD = 0.73$). Although interestingly, fewer reported making sure the child tries new foods ($M = 3.14$, $SD = 1.42$) Making sure the child eats everything on their plate was reported as the least important mealtime practices ($M = 2.04$, $SD = 1.21$).

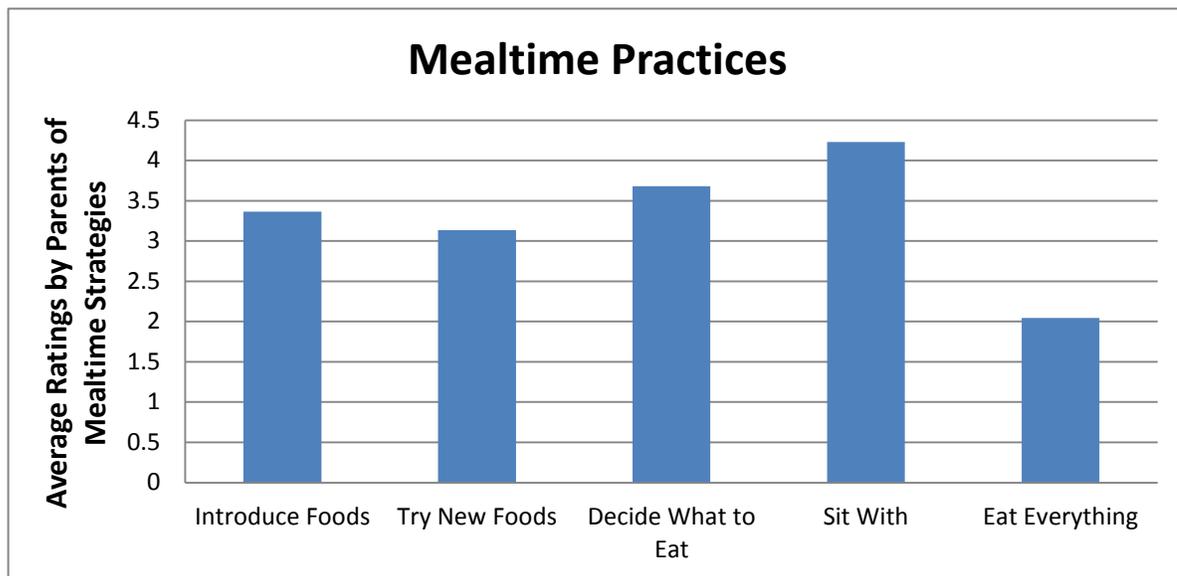


Figure 4. Average implementation of certain mealtime practice using a 1-5 Likert Scale

Analysis of parent emotions and the relationship to mealtime behaviors show the parents who tend to be more stressed are also more worried, frustrated, anxious, and feel less successful. Results indicate a statistically significant relationship between verbal behavior and stress $r(23) = .444, p = 0.038$. In fact verbal behavior has a stronger effect on parental stress and distress than throwing $r(23) = 0.024, p = 0.916$ or kicking $r(23) = 0.407, p = 0.060$. Even though results show kicking, throwing and verbal behaviors occur often, it is the verbal behavior that seems to stress the parents out the most (see Table 1).

Results also show a correlation between parental worry and verbal behavior $r(23) = 0.490, p = 0.021$. The relationship between parent anxiousness and verbal behavior is nearly significant at $r(23) = -0.419, p = 0.052$, in addition to parental feeling of success and verbal behavior $r(23) = 0.412, p = 0.056$.

Table 1. Correlation between parent emotions and child's mealtime behaviors.

		Stress	Anxious	Frustrated	Successful	Worried	Kicking	Throwing
Anxious	r	0.705						
	p	0.000						
Frustrated	r	0.835	0.639					
	p	0.000	0.001					
Successful	r	0.609	0.729	0.748				
	p	0.003	0.000	0.000				
Worried	r	0.716	0.663	0.682	0.699			
	p	0.000	0.001	0.000	0.000			
Kicking	r	-0.407	-2.96	-.223	-0.387	-0.494		
	p	0.060	0.180	0.319	0.075	0.019		
Throwing	r	0.024	-0.168	-0.041	-0.064	-0.211	0.432*	
	p	0.916	0.455	0.855	0.776	0.347	0.045	
Verbal	r	-	-0.419	-0.292	-0.412	-0.490*	0.818**	0.479*
	p	0.444*	0.052	0.187	0.056	0.021	0.000	0.024
		0.038						

*Correlation is significant at the 0.05 level

**Correlation is significant at the 0.01 level

Additionally, data shows if a child is kicking they are likely to be throwing and much more likely to be verbal, meaning kicking is significantly related to both verbal $r(23) = 0.818, p = 0.000$ and throwing $r(23) = 0.432, p = 0.045$ behaviors (see Table 2).

When one behavior occurs others are likely to occur as well, and while these three behaviors occur together, the one that causes the most stress and anxiousness is verbal.

Table 2. Correlation between parent emotions and child's mealtime behaviors.

		Kicking	Throwing
Throwing	r	0.432*	
	p	0.045	
Verbal	r	0.818**	0.479*
	p	0.000	0.024

*Correlation is significant at the 0.05 level

**Correlation is significant at the 0.01 level

DISCUSSION

The purpose of this research was to determine the emotional responses parents feel during mealtime with their child/children diagnosed on the autism spectrum. Additionally, the aim of the study was to determine whether the negative emotions parents felt were enough to seek additional information that would provide support during mealtime, making the process of mealtime less stressful and more successful. Interestingly, the result of this study demonstrated that even though various behaviors occur during mealtime in addition to high parental stress, the majority of parents do not wish to receive additional resources to support them.

Summary of Major Findings

To investigate parents overall emotions during mealtime, parents were asked to respond with a simple “yes or no” in regards to whether mealtime was stressful; 15 participants out of 24 reported mealtime being overall stressful. Additionally, participants were asked to rank feelings of stressfulness, anxiousness, frustration, success and worry on a scale of 1 to 7. Review of this analysis show parents experience stress over any other emotion addressed at mealtimes; with feeling of frustration reported as the second highest emotion experienced during mealtimes. Interestingly, parents who reported being stressed also tend to be more worried, frustrated, anxious, and feel less successful. Therefore, not only is stress a factor in parent’s successfulness, but various other emotions play a role in their overall well-being. Due to these findings, one would think additional information

would be much desired to improve one's stability. Thus, further research might investigate the perceptions parents have in regards to denying additional support and the factors that may play a role in their decision to turn down additional help. For example, parents may not have the time to practice new strategies, they may think there is no hope for their child when it comes to improving mealtime successfulness, or they simply are happy with what is occurring at mealtimes even though they report being stressed.

Analyses of results show specific factors that influence parent emotion and child successfulness. Behaviors that occur during mealtime such as verbal protest or screaming are significantly related to parental stress, with verbal protesting ranked as the number one problem behavior expressed during mealtime. Research into problem behaviors and parent emotions during mealtime is extremely limited. However, Hudock's (2013) study revealed that stress among parents occurs frequently across different situations. He found that problem behaviors that occur with children and their social skills also contribute to overall stress in parents (Hudock, 2013).

Several aspects of this survey suggest that parents would benefit from additional resources and support. However, interestingly, out of 19 participants 12 reported no desire to receive further information on behavioral strategies that would assist them and their child during mealtime. Also of note, out of 23 participants 18 parents currently do not receive any behavioral services. One might conclude that parents have adapted a functional way of getting through mealtime with their child even though mealtimes are stressful. Also, because most parents have not experienced the benefits of behavioral services, they may not be aware of the possible benefits. Other possible explanations may

include feeling that having additional information would create extra work for the parents, perhaps resulting in more stress. Parents may wish to see immediate results and therefore may not be on board until they see a product that works for them. Further research into the reasoning behind why parents do not wish to receive more information may help one adapt a handy and useful way of providing parents the essentials that would make mealtimes more successful. Also of note, due to the nature of Applied Behavior Analysis (ABA), most of the information that would benefit the parents and child around mealtime would also benefit them in other areas of concern.

The survey did not include other options such as training, so it may be that while parents indicated a lack of interest in additional information, some might be interested in another form of support. Future research should explore a broader range of supports to determine if there are other opportunities to serve these parents. Additionally, perhaps future research might investigate strategies that would encourage parents to experiment with behavioral interventions that could be applied at home, such as training programs geared towards providing parents the tools necessary to mediate mealtime behaviors.

Limitations to the Study

Accessing the population of parents needed for this study was a difficult task. Due to confidentiality concerns, accessing parent information from various companies was impossible. The main method of obtaining results was through various autism events around Humboldt County, which resulted in a small sample size. Because the three events I attended to recruit participants were family and fun driven, most parents were

occupied with having fun and keeping an eye on their children which may have reduced the quality of the data collected.

Another limitation related to instrumentation involves Question number 7 which asks participants to rate their level of emotions on a scale of 1 to 7 with 1 being stressed and 7 being calm. To some participants this may seem backward; thinking the higher number would indicate a higher stress level. Because of this, the scale was reversed to analyze results.

Future Directions

Results from this study indicate a clear problem for parents and their children around mealtime. However, there is limited research in regards to mealtime and the emotions parents feel. Therefore, future research that investigates the parent's emotions during mealtime would be beneficial to many people. An observational study would allow researchers to gain first-hand information on what occurs during mealtime and the affect it has on the parent's emotions. Additionally, discovering through direct observation the ways in which the parent interact with the child might guide researchers to discover new techniques that would benefit the parent more than what is already available.

Furthermore, investigation into particular foods children eat and the effect they have on their challenging behavior could also be beneficial. Some research has investigated the nutritional affect gluten or casein has on children diagnosed with autism, however there is limited research that explores specifically challenging behaviors that

occur when certain foods are consumed. Furthermore, investigating particular ages separately and the behaviors that occur prospectively during mealtime may be beneficial to some researchers. Likewise, assessing the parent stress level at each age might allow researchers to gain a better understanding of particular behavioral strategies that would work best with each age.

In conclusion, this study found parents experience high levels of stress and frustration during mealtime, particularly when their child is lashing out with verbal behaviors, yet still are not interested in potentially beneficial information. One might conclude that parents prefer to receive some kind of one-on-one training rather than receiving information in the form of a verbal lecture, or written down on paper. Additionally, although some parents experience difficulty at mealtime, they are content enough with their routine and are not interested in expending energy in learning possibly useful techniques that could improve the situation.

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APPENDIX

Mealtime Survey

The following survey explores how children with special needs and their parents experience mealtimes in an effort to identify strategies that support successful mealtime experiences.

1. How many children live with you? _____
2. How many of these children have been diagnosed with autism? _____
3. How old are your children diagnosed with autism _____
4. Are you a single parent/guardian raising a child with special needs? Yes No
5. Are mealtimes often stressful due to your child's behaviors? Yes No
6. If so, do you receive any type of behavioral support around mealtime? Yes No

7. Mealtimes with your special needs child make you feel:

a.	Stressed	1	2	3	Neutral	5	6	7	Calm
b.	Anxious	1	2	3	4	5	6	7	Peaceful
c.	Frustrated	1	2	3	4	5	6	7	Satisfied
d.	Unsuccessful	1	2	3	4	5	6	7	Successful
e.	Worried about behavior	1	2	3	4	5	6	7	Confident in good behavior

9. Please indicate how frequently the following occur:

	Never	Rarely	Sometimes	Often	Always
a. Mealtimes take a lot of effort and energy	1	2	3	4	5
b. My child exhibits kicking behavior at mealtime.	1	2	3	4	5
c. My child exhibits food-throwing behavior during mealtimes.	1	2	3	4	5
d. My child exhibits screaming/verbal protest during mealtime.	1	2	3	4	5
e. My child gets my full attention at meal times.	1	2	3	4	5
f. Other challenging behavior_____	1	2	3	4	5

10. Please indicate how frequently the following

occur:

	Never	Rarely	Sometimes	Often	Always
a. I introduce new foods for my child to try.	1	2	3	4	5
b. I let my child decide what and how much they wish to eat.	1	2	3	4	5
c. I make sure my child eats everything on their plate.	1	2	3	4	5
d. I make sure my child tries all foods on their plate.	1	2	3	4	5
e. I sit down with my child at meals.	1	2	3	4	5

13. How often do you:

A. Encourage eating behaviors by consistently rewarding some behaviors but not others

1. *Never* 2. *Rarely* 3. *Sometimes* 4. *Often* 5. *Always*

B. Wait out with the child when they try to avoid eating certain foods

1. *Never* 2. *Rarely* 3. *Sometimes* 4. *Often*
5. *Always*

C. Punish bad behavior

1. *Never* 2. *Rarely* 3. *Sometimes* 4. *Often*
5. *Always*

D. Use verbal or non-verbal cues encouraging the child to use appropriate behavior and eat selected foods

1. *Never* 2. *Rarely* 3. *Sometimes* 4. *Often*
5. *Always*

14. Do you have any in-home behavioral therapy services for your child diagnosed with autism? Yes No

If yes, please describe below what they focus on.

15. Do you want to learn more about mealtime behavioral strategies?

Yes No

If yes, please explain what you would like to learn more about.