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Parents' Attitudes and Beliefs Towards Dietary Behaviors of Children with Autism Aged 5-13 Years

Subashree Narayanan
n00173731@unf.edu

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Parents' Attitudes and Beliefs Towards Dietary Behaviors of Children with Autism Aged 5-13 Years

Prepared by:

Subashree Narayanan, MSH

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Doctoral Project Committee Members

Dr. Andrea Y Arikawa, PhD, MPH, RDN, LDN, FAND

Associate Professor

Co-Director, Doctorate in Clinical Nutrition

Department of Nutrition and Dietetics, Bldg 39, room 3046

University of North Florida

andrea.arikawa@unf.edu

Dr. Anita Fuglestad, PhD

Instructor

Department of Psychology

College of Arts & Sciences

University of North Florida

anita.fuglestad@unf.edu

Dr. Jen Ross, DCN, RD, LD/N, FAND

Assistant Professor

Director, Didactic Program in Dietetics

Department of Nutrition & Dietetics

Brooks College of Health

University of North Florida

j.ross@unf.edu

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Contents

Acknowledgments.....	2
Introduction.....	7
Special needs.....	8
Autism Spectrum Disorder	9
Diagnostic criteria for ASD	9
Characteristics of ASD	11
Diagnostic Criteria for ARFID ⁷	13
Parenting in ASD	14
Parent Behavior and Parenting Style	15
Prevalence of feeding difficulties in young children	16
The Role of Nutrition in ASD.....	17
Food Selectivity and ASD	17
Factors that could determine food selectivity in children with ASD.....	18
Nutrient Intake and ASDs.....	19
Nutrition and children with special needs.....	20
Influences of Maternal Feeding Styles During Infancy and the Toddler Years	21
Parenting and Feeding Styles in Families with Typical Growing Children	22
The Current State of Diets of Typically Growing Children	25
Parents as Providers, Models, and Regulators	26
Dietary Restrictions as interventions in ASD	29
Gluten-Free/Casein-Free Diet (<i>GF/CFD</i>).....	29
Ketogenic Diet (<i>KD</i>).....	30
The Specific Carbohydrate Diet (<i>SCD</i>)	31
Parent's Attitudes and Beliefs and Children's Dietary Behavior Intake	31
Autism's Clinical Companions: Frequent Comorbidities with ASD.....	34
Feeding guidelines for children with feeding difficulties.....	37
Role of Dietitian, Therapist and Physician	37
Statement of the Problem.....	40
Theoretical Framework	42
The Health Belief Model	42
Conceptual Framework.....	46

Research Aims	47
Methodology	48
Study Design.....	48
Study participants and inclusion criteria.....	49
Data Collection	50
Consent Form (<i>Appendix A</i>).....	50
General Questionnaire and Pertinent Information (<i>Appendix B</i>).....	50
Nutrition and Health Awareness Questionnaire (<i>Appendix C</i>).....	51
Brief Autism Mealtime Behavior Inventory (<i>BAMBI</i>) – (<i>Appendix D</i>).....	51
Dietary Recall (<i>Appendix E</i>).....	51
Data Analysis	52
Results.....	55
Discussion	63
Strengths and Limitations	70
Conclusions.....	71
Implications of the study.....	71
Additional Interesting Observations	74
Appendix A.....	76
Appendix B	79
Appendix C	80
Appendix D.....	81
Appendix E	82
References.....	83

List of Figures

Figure 1:Special Needs Issues in Children	8
Figure 2: Food Selectivity.....	18
Figure 3: Synopsis of ASD Food selectivity on nutritional status, anthropometric features and clinical conditions	20
Figure 4:Parenting Styles.....	23
Figure 5:Feeding Styles	23
Figure 6:Division of Responsibility in Feeding.....	24
Figure 7: Division of Feeding.....	25
Figure 8: Healthy Eating and Behavior	46
Figure 9: Map of Indian Participants	57
Figure 10: Map of USA Participants	57
Figure 11: Radar plot of the components of the Healthy Eating Index (HEI) of Children ages 5-13 Diagnosed with Autism Spectrum Disorder for all participants.....	58
Figure 12:Radar plot of the components of the Healthy Eating Index (HEI) of Children ages 5-13 Diagnosed with Autism Spectrum Disorder from US & India	59
Figure 13:Parent Tools to aid with improving dietary behavior in children, with respect to Parent's Barriers and Self-efficacy.	73
Figure 14:Dietary Patterns in children from India (Panel A) & US (Panel B), indicating the differences of food intake.	75

List of Tables

Table 1:Food Groups- Daily Servings by Age	20
Table 2:Guidelines for parents with feeding.....	28
Table 3: Sample Size Calculation	52
Table 4: Demographics, gastrointestinal symptoms and sleep status of children with autism.....	55
Table 5: BMI Percentile Analysis.....	56
Table 6: Healthy Eating Index Scores for all Components.....	59
Table 7:Spearman correlations between parents’ perceived barriers, self-efficacy and dietary behavior of children with autism for all participants.	60
Table 8: Daily intakes of energy and nutrients of children with autism, compared with the dietary reference intake (DRI)	60
Table 9: Spearman correlations between parents’ perceived barriers, self-efficacy and nutrient intake of children with autism for all participants.	60
Table 10: Spearman correlations between parents’ perceived susceptibility, severity and dietary behavior calorie intake of children with autism.....	61
Table 11:Barriers & Self-efficacies in Parents	61
Table 12: Common Dietary Behavior Concerns.....	62
Table 13: Coefficients of the logistic regression model for prediction of gastrointestinal symptoms in children with autism for all participants.	62
Table 14: Median of Dietary Variables by Intake of Gluten-Free Casein Free (GF/CF) diet of children with autism living in the U.S.	63

Introduction

Children with special needs may be at increased risk for malnutrition due to nutritional disorders and compromised nutritional status.¹ Nutritional risks are indicated but not restricted to altered growth, varied energy needs, nutrient interactions with medication, metabolic disorders, impaired ability to utilize nutrients and poor self-feeding skills.² A compromised nutritional status could hinder response to therapies and active participation in day to day activities. On the other hand if a child is well-nourished then he/she will have good alertness and resilience to participate in therapies, activities at school, and social interactions and refrain from fewer illnesses and improved skills to cope up.¹ The child may be increasingly independent if he/she has good self-feeding skills and hence in good health condition. It can benefit the child's insight of self and the caregivers' insight of their abilities to meet the child's needs.¹

Parents play a pivotal role in the upbringing of children in every aspect of their life. The extent of parent's involvement and from the early age onto adulthood, impacts the child's well-being. Similarly, parent's attitudes and their behavior towards healthy eating reflects on the child's eating habits and thus their nutritional health. It is documented that children with Autism Spectrum Disorder (*ASD*) are five times more likely to have challenges during mealtime such as outburst, extreme food selection and stereotype eating behaviors.² Overcoming these nutritional challenges of children with special needs, is an intricate issue that is sometimes within and sometimes beyond a parent's understanding. Yet to the extent possible, it is important to ensure that our children relish the food they eat for its color, flavor, and rich-texture, and to get them involved in sports and physical activities and to be able to respond to all therapies. When a child is diagnosed with *ASD*, it is very normal for parents to research for ways to improve their child's quality of life. Children's day to day demands may be overwhelming for the parents and cause stress for them. Sometimes

parent's beliefs and attitudes in parenting style and dietary habits could hamper their child's healthy growing. Thus, it would be interesting to assess parent's attitudes and beliefs with respect to their child's intake and dietary behaviors. This could further create a scope for future studies and bridge a gap for health care professionals, feeding therapist and nutritionists who can then provide their expertise depending on the need. Medically if the gap is bridged, then children with Autism can lead a normal life, like that of the general population. The purpose of this study is to identify shortfalls in terms of roadblocks or limitations of parents, catering to their child's dietary needs and how that may affect the dietary behavior and health status, in the growing years.

Special needs

Special needs are a broad term for a wide range of diagnoses, from those that have a quick solution to those that will be a lifelong challenge and those that are quite mild to those that are severe, as illustrated in figure 1.³ Special needs include developmental delays, medical conditions, mental disabilities, and congenital conditions that require special attention so children can reach their capacity. For whatever the reason be, the term is useful. It can facilitate to obtain needed services without much trouble, set suitable goals, and comprehend the needs of the child and the physical and mental agony the family may face. The population of this study will include only children with autism spectrum disorder (*ASD*).



Figure 1: Issues in Children with special needs

Autism Spectrum Disorder

Autism or autistic spectrum disorder (*ASD*)⁴ is a wide ranging neurodevelopmental disorder engirdling impairments in social interaction, language skills, communication, and self-imaginative play. It also encompasses very restricted, repetitive, continuous, and rigid patterns of behaviors, activities, and interests. Autism spectrum disorder embrace conditions that were previously considered different — Autism, Asperger's syndrome, childhood disintegrative disorder and an unclear form of pervasive developmental disorder.⁵ Some people continue to use the phrase "*Asperger's Syndrome*" which is usually thought to be at the lower end of autism spectrum disorder. Autism spectrum disorder begins very early as a child and transpires to cause problems functioning in society — socially, at school environment and at work with colleagues, for example. Commonly children show symptoms of ASD within the first year of life. A small group of children seem to develop at normal pace in the first year, and then go through a period of retreat between 18 and 24 months of age when they show signs of developing symptoms of autism. Though there is no proven cure for autism spectrum disorder, intensive and early intervention can make a significant difference in the lives of many children. The disorder has a varied phenotype, in relation to both severity and symptoms.⁶

Diagnostic criteria for ASD

In 2013, the American Psychiatric Association released the fifth edition of its Diagnostic and Statistical Manual of Mental Disorders (*DSM-5*).⁷ The DSM-5 is used as the standard reference now by the healthcare providers to diagnose conditions related to mental and behavior, including autism.^{8,9}

- A. “Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
 2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
 3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.”
- B. “Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history:
1. Stereotyped or repetitive motor movements, use of objects, or speech (*e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases*).
 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (*e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day*).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (*e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests*).
 4. Hyper- or hyperactivity to sensory input or unusual interest in sensory aspects of the environment (*e.g. apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement*).”
- C. “Symptoms must be present in the early developmental period (*but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life*).”
- D. “Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.”
- E. “These disturbances are not better explained by intellectual disability (*intellectual developmental disorder*) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.”

Characteristics of ASD

As we know, *ASD* is an intricate behavioral syndrome that usually occurs in the first 3 years of life, and which affects many aspects of normal development of mental health. The consequences and severity of ASD symptoms vary from person to person, and the type and complexity of behavior vary. Verbal and nonverbal intelligence (IQ) scores vary greatly in ASD¹⁰

and Restrictive and Repetitive Behaviors (*RRB*) can range from minimally rigid sports behaviors to higher-order behaviors, such as equality requirements.¹¹ Among the postulant elements of ASD there are seriously robust genetic components, in which passing down via generations has been anticipated to be from 60%^{12,13} to greater than 80%.¹⁴ Next to genetic elements, the environmental elements which can be involved withinside the boom of ASD chance appear to include: pollutants of air, insecticides exposure, infections throughout pregnancy, nutritional elements, gestational diabetes, stress, any medications, unexpected infections, inflammatory situations or antibiotics intake throughout pregnancy.¹⁵ Possible dietary risk factors include but not limit to prenatal and perinatal folate and iron status or polyunsaturated fatty acid (*PUFA*) intake of the mother.¹⁶ Among other diseases associated with ASD, it is easy to find dietary restrictions, dietary problems, and intestinal diseases. In fact, children with autism are very picky about food. (“*Picky Eaters*”). The result is a disorder in eating which is commonly known as Avoidant/Restrictive Food intake Disorder (*ARFID*). Difficulties such as only eating selective foods, intermittent fasting and extremely anxious about foods and mealtimes are often observed. Most of them show aversion to certain food color, texture, smell, or other food problems.¹⁷ This impacts directly on the effect of diet quality, deficiency in nutrients and, on the composition of gut microbiota. These problems are not always comprehended well which results in, parents/caregivers and the individuals often reporting in feelings of stress, anxiety, sense of helplessness and guilt. For some, these conditions can be addressed relatively with ease having the right support and for others the issues with eating can have a long and stressful impact resulting in weight loss and/or malnutrition, increased loneliness, no social interaction, and stigma. Very effectively many with autism now meet the requirement for an extra diagnosis of ARFID. This can facilitate to a better comprehension of the dietary problems and receive more support from professionals in the field.

Diagnostic Criteria for ARFID⁷

“An eating or feeding disturbance (*e.g., apparent lack of interest in eating or food; avoidance based on the sensory characteristics of food; concern about aversive consequences of eating*) as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (*or more*) of the following: “

- “Significant weight loss (*or failure to achieve expected weight gain or faltering growth in children*).
 - Significant nutritional deficiency.
 - Dependence on enteral feeding or oral nutritional supplements.
 - Marked interference with psychosocial functioning. “
- “The disturbance is not better explained by lack of available food or by an associated culturally sanctioned practice.”
- “The eating disturbance does not occur exclusively during anorexia nervosa or bulimia nervosa, and there is no evidence of a disturbance in the way in which one’s body weight or shape is experienced. “
- “The eating disturbance is not attributable to a concurrent medical condition or not better explained by another mental disorder. When the eating disturbance occurs in the context of another condition or disorder, the severity of the eating disturbance exceeds that routinely associated with the condition or disorder and warrants additional clinical attention.”

Most ASD individuals that have a co-morbidity of GI disorders could be affected by unique food intake that may aggravate ASD symptomatology.¹⁸ Immune dysfunction and gastrointestinal (GI) inflammation are also typical in individuals with ASD and add to complexity of behaviors.^{18,19} Many children with ASD have also been identified to exhibit abnormalities in GI functions,

including: excess intestinal permeability,²⁰ general microbiota alterations^{21,22} and infection in the gut by cresol-producing *Clostridium difficile*.²² Continued research on the human gut microbiota has shown that there is a close relationship between the brain and intestinal functions, called the "*gut-brain axis*", which includes the immune system, hormones, brain cells, and metabolic pathways.²³ The gut-brain axis might also additionally make a contribution to the signs and symptoms related to ASD, because it has been suggested that cytokines originating from infection within the gastrointestinal tract might also additionally move the blood-brain barrier and cause an immune response (*come back*) within the mind, which in flip can have an effect on behavior.²⁴

Parenting in ASD

Parenting is the process of nurturing and supporting the physical, non-cognitive, social, and civilized and academic development of a child from childhood to adulthood. Parenting refers to the complexities of upbringing a child and not solely for a biological relationship.²⁵

The processing of parenting kids with ASD has a complex history, beginning with Kanner's²⁶ principle that moms have been to be responsible for his or her child's autism in 1943. Kanner²⁶ theorized that autism is probably as a result of the "*Refrigerator Mother*" moms who have been bloodless and emotionless. The concept of "Refrigerator Mother" has been recognized by other famous theorists in the field, the most famous of which is Bettelheim in 1967. There is no scientific evidence to show that mothers are insensitive, insensitive to children's needs, and slow to react to children's emotions and emotions and hence the cause of their children's autism.²⁷ With certainty, it's far properly popular that moms aren't the reason of autism of their youngsters. For youngsters with ASD, mother and father have become worried to a excellent quantity of their child's treatment, and in few cases, they function the preliminary and essential supply for catering

the treatment.^{28,29} Parental involvement is crucial because the birth of children with ASD brings many different challenges to the family system. For example, due to the transition problems faced by many children with ASD, family planning is more flexible; parents often lose their temper due to children's behaviors. (*Voluntarily or involuntarily*) are forced to avoid attending public gatherings; they are often forced to assume parenting responsibilities, which may interfere with parenting duties and have a negative impact on family finances.³⁰ Many more challenges to the family exists across the growing and nurturing of the kid with ASD, and have vital shadows on parents' mental stress, touching parents' mental and social well-being and impact family functioning and bonding.³¹

Parent Behavior and Parenting Style

A comparison of child rearing fashion between children with ASD, Anxiety and Typical Development (TD) was conducted in a study. This study found that guardians of kids with anxiety elaborated encounters of exaggerated anxiety themselves compared with oldsters of children with ASD and TD children, though this wasn't connected with any domains of parenting style. In contrast,³² though parents of youngsters with anxiety elaborated comparable levels of depressive symptoms to folks of TD children, a big association with use of psychological management was seen among parents of children with anxiety. These furthermore elucidates distinct patterns of association between parent symptoms and parenting vogue between parents of youngsters with anxiety and of TD children. In contrast, parents of children with ASD have higher levels of depressive symptoms than parents of children with anxiety disorders and parents of TD children. However, unlike parents of children with anxiety disorders, the depressive symptoms reported by parents of children with ASD have nothing to do with parental behavior, further

emphasizing that children's behavioral symptoms may play a role. In this clinical group, the configuration of parental behavior is more dominant.

Prevalence of feeding difficulties in young children

It is clear from the literature^{33–35} that children with special needs have feeding difficulties. The term feeding difficulties is a broad term used to describe a variety of feeding or mealtime behaviors perceived as problematic for a child or family. This may include behaviors such as Picky Eating, Prolonged mealtimes, Disruptive Behaviors or Restricted Variety of Foods.³⁶ Reviewing further, feeding difficulties are also commonly seen in typically growing children. The prevalence of feeding difficulties is approximately 25%–35% in children with normal intellectual and adaptive development.³⁶ For those with developmental disabilities, prevalence increases to 40%–80%. Specifically, the prevalence of feeding difficulties challenges is nearly 90% in children with ASD.³⁷ A 2008 parental survey reported, the prevalence of feeding problems was 41.1% in children between the age 1 to 12 years.³⁸ This survey reported that picky eating was the most prevalent feeding-related problem (81.7%), followed by prolonged mealtimes (43.1%).³⁸ Picky eating is a common behavior in early childhood. There's not one or the other a generally accepted definition of picky eating, nor is there assertion on the leading instrument to recognize it. Early feeding difficulties, late introduction of lumpy foods at weaning, pressure to eat and early choosiness, especially if the mother is worried by this; are some causes of picky eating. Protective factors include the provision of fresh foods and eating the same meal as the child.³⁹ The consequences for the child's diet include poor dietary variety and a possible distortion of nutrient intakes, with low intakes of iron and zinc (*associated with low intakes of meat, and fruit and vegetables*) being of particular concern.⁴⁰ Constipation in picky eaters could be attributed to the fact of inadequate intakes of dietary fiber, as a result of inadequate of fruits and vegetables. There

may be developmental difficulties in some children with persistent picky eating. There is little evidence, for a consistent effect of bring a picky eater on growth trajectories.⁴¹ There may be a little subgroup of children within whom picky eating does not resolve who could be at risk of either thinness during adolescence, or of developing an eating disorder or adult picky eating: these children need to be distinguished at an early age to provide support, monitoring and educate parents appropriately.³⁸ Strategies for avoiding or ameliorating picky eating include repeated exposures to unfamiliar foods, parental modelling of eating fruit and vegetables and unfamiliar foods, and the creation of positive social experiences around mealtimes.⁴¹ The prevalence of feeding difficulty, maybe higher in children with failure to thrive than in the general population, as it associated with nutritional deficiency and growth faltering.

The Role of Nutrition in ASD

Food Selectivity and ASD

Neurotypical children, particularly preschoolers, are regularly alluded to as “*Picky Eater*” and may display a preference for certain foods and dismissal of others.⁴² This behavior can be more pronounced in children with ASD, and it can starts at an early age resulting in a real food selectivity framework. Additionally, these patterns in behavior towards food selectivity can have adverse consequences to the children’s nutritional status and health. From a nutritional standpoint this could lead to an inadequate caloric intake.⁴² In fact, DSM-5 emphasizes the importance of food regulation in children with ASD, although it is not considered a diagnostic criteria.¹¹

Children with ASD are at risk for malnutrition either due to an excess of intake of certain nutrients or due to a deficit of intake of others.⁴³ Food selectivity seems to be most influenced by texture, followed by appearance, taste, scent, and temperature. There is also great resistance to try new foods. All of these factors lead to a limited number of foods being consumed by children with

ASD as seen in Figure 2.⁴⁴ ARFID can be heightened and more complex; routines and ritualistic practices around food can be more rigid and inflexible due to additional anxiety about alterations and a child with extreme autism often has more problems responding and recognizing to internal body states such as being full or hunger.⁴⁵



Figure 2: Food Selectivity

Factors that could determine food selectivity in children with ASD

Some of the most common foods accepted by children with ASD are processed foods, such as high starch foods and snacks. On the other hand, fruits, vegetables and protein are often rejected.⁴⁶ An increased consumption of snack foods and calorie-dense foods can lead to excessive gain in weight, with related higher rates of obesity in children with ASD, in contrast to typically growing children.⁴⁷ Nadon et al⁴⁸ found that processing sensory information, was not apparent in

nearly 90% of preschool and school age ASD children, related to touch, scent, locate, and hearing, within the same way as their ordinarily creating peers.⁴⁸ Some studies observed that children with ASD had strong food preferences,⁴⁹ and other contributing factors for food selectivity reported by other studies are the presentation of food at the table, and the specific tableware and utensils used.^{44,50}

Nutrient Intake and ASDs

The selectivity of food in children with ASD poses great risk for nutritional deficiencies.⁵¹ Though, literature nonetheless suggests conflicting outcomes concerning the chance of deficits in nutrition in children with ASD,⁵² particularly as a result of children with ASD are compared with typically developing children. In many studies, children with ASD display a extensively smaller style of meals selectivity, however authors document no typical variations of their overall calories, carbohydrates, or fats intakes^{53–56} it shows that their satiety mechanism is not affected. The protein intake is sufficient or roughly the same as the intake of a normally developed child.^{54–56} It has been observed that children with ASD eat less vegetables and eat more high-calorie foods,⁵⁷ which is why a large number of ASD children have insufficient fiber intake.^{53,55,58,59} A substantial number of children with ASD had insufficient intake of micronutrients. In particular they showed deficiencies of calcium,^{52,54,55} iron,⁵⁵ zinc,⁵⁹ potassium,⁶⁰ copper,⁶⁰ and vitamin A,⁵³ vitamin D,^{51,55,56} vitamin E,^{53,55} riboflavin,⁵⁵ vitamin C,⁵⁷ vitamin B-12,⁵¹ folic acid⁶¹ and choline.⁵⁹ Consumption of sodium in excess was reported⁵⁸ presumably due to excess consumption of packaged foods. Several studies have reported that compared with the control group (DT), ASD children have lower bone development, lower mineral density, and an increased risk of fractures. Although they are well developed by anthropometry, they are related to dietary calcium and vitamin D deficiencies.⁶² The dietary choices of children with ASD are shown in Figure 3 below..⁴⁴

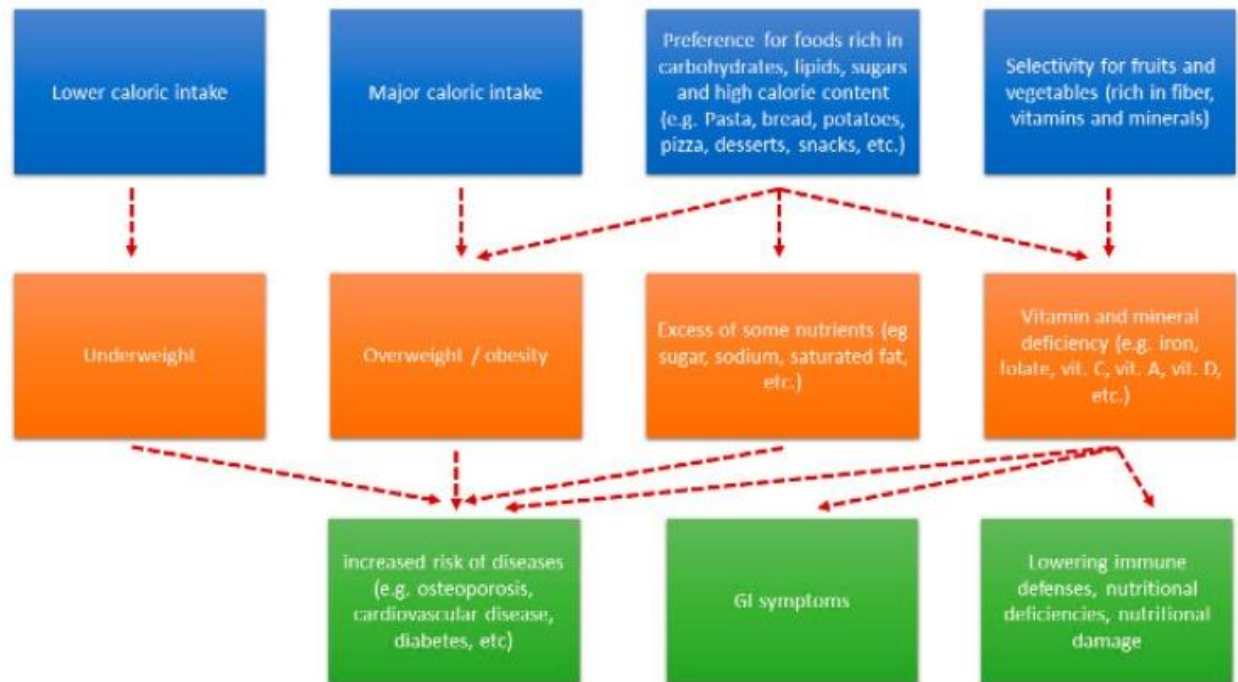


Figure 3: Schematic presentation of Food selectivity on nutritional status, anthropometric features, and clinical conditions in ASD

Consequently, meals selectivity and an insufficient nutrient consumption ought to boom the hazard of malnutrition in ASD that in the long run ends in both weight problems or undernutrition. Furthermore, it's been proven that those situations are related to an altered composition and variety of the gut microbiota as compared to wholesome individuals.^{33–35} In order to select the best nutritional approach for patients with ASD, it is important to consider the influence of nutritional status on the intestinal microbiota.

Nutrition and children with special needs

Table 1: Food Groups- Daily Servings by Age

Food Groups: Daily Servings by Age					
	2-3 Yrs	4-5 Yrs	6-8 Yrs	9-17 Yrs	18+ Yrs
Grains (oz)	3 oz	5 oz	5 oz	6 oz	6 oz
Veggies (cup)	1/3 cup	½ cup	2 cups	2 ½ cups	2 ½ cups
Fruits (cup)	1/3 cup	½ cup	1 ½ cup	1 ½ cup	2 cup
Dairy (cup)	2 cups	2 ½ cups	2 ½ cups	3 cups	3 cups
Protein (oz)	2 oz	3 oz	5 oz	5 oz	5 ½-6 oz

In table 1,⁶³ the daily servings from different food groups by age is tabulated by professionals working with the special need children. The age spanned here is from 2 to 18 plus years. The preferable amounts of servings in each food group has been identified for children with special needs in their specific age groups. This table would be an easy ready reckoner for parents and caregivers to follow in providing food to their children daily. This will also help them plan the menu and distribute the food groups in advance and help them consider all the food groups throughout the course of the day.

Influences of Maternal Feeding Styles During Infancy and the Toddler Years

Although as mentioned above, there are nutritional difficulties at different stages of life, but learning good eating habits develops from birth to adolescence. The first year of life is a stage of rapid physical, social and emotional growth, and eating habits also develop at this stage. In the first year, babies move from a single food (*such as breast milk or infant formula*) to a more typical adult diet with multiple foods. This transformation allows babies to learn about food by directly experiencing and understanding other people's eating habits.⁶⁴

There is evidence that breastfeeding and parenting practices play an important role in shaping long-term eating behavior in the first few years of life.⁶⁴ Breastfeeding is recommended as the best nutritional method for the first 6 months of life,⁶⁴ partly because of increasing evidence that breastfeeding is beneficial. Affect the development of children's eating behavior in the future.

64-66

Breastfeeding plays an important role in cultivating the baby's response to the inherent signs of hunger and satiety,⁶⁴ and helps to develop self-regulation during breastfeeding.⁶⁴ Breastfeeding also has a positive impact on subsequent eating behavior since it may promote acceptance of flavors in the maternal diet that are passed through breast milk. Breastfeeding also

has a positive impact on future breastfeeding behavior, because it can promote the mother's absorption of the aroma transmitted through breast milk.⁶⁷ Therefore, breastfed babies will be exposed to more different tastes depending on the type of mother's diet, and this exposure will affect the food intake during the transition to solid food, and later life.⁶⁸ In a sense, breastfeeding gives babies the opportunity to experience the tastes of their mother's diet early and repeatedly, creating a taste connection and encouraging babies to accept familiar tastes when they appear in their diet.⁶⁷ Depending on changes in the mother's diet during breastfeeding, new food intake and possibly more varied diets in later life.^{68,69}

Literature so far, validates the fact that children irrespective of a developmental delay or typical growth exhibit unique dietary behaviors from infancy, toddler through adolescent ages. The exhibited characteristic of eating is attributed to parenting, adult modelling and feeding styles (*including breast feeding during infancy*). Hence it is important to know the different parenting and feeding styles and adapt to the most suitable to foster healthy eating behaviors in the child.

Parenting and Feeding Styles in Families with Typical Growing Children

Four parenting styles⁷⁰ have been identified and are related to two variables: the level of the parents' expectations and the level of supports given to the child as illustrated in figure 4.⁷¹

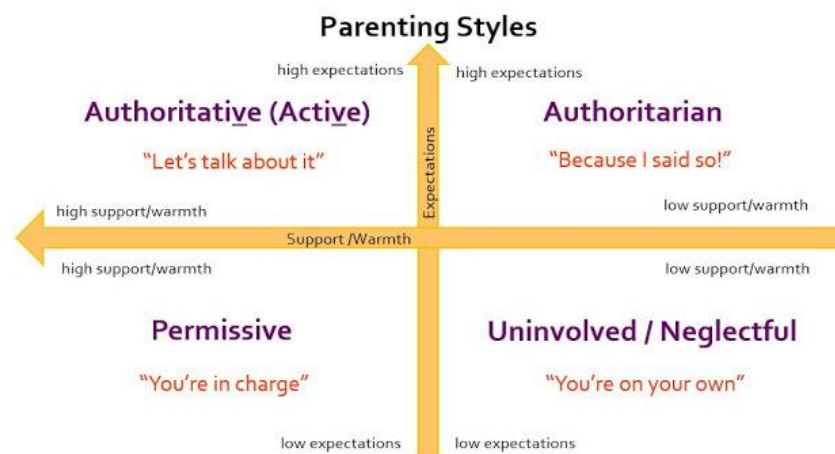


Figure 4: Parenting Styles

Authoritative/Active parenting style has been recommended by psychologists and child development experts providing the strong support needed to help children reach the high expectations that are set up for them.⁷² Children of authoritative parents are the happiest and most capable in comparison with other parenting styles. Their parents provide clear boundaries and expectations with fair and consistent discipline. Their parents are resilient and willing to adjust their responses based on the circumstances. They listen to their children and encourage their children to discuss options and express their opinions which encourages autonomy and reasoning skills. The children additionally have better emotional control & self-regulation. Since they are self-confident about their ability to learn new things, they have elevated levels of academic performance.⁷⁰ *Satter*,⁷⁰ *Hughes*⁷² and *Birch*⁷³ emphasized in their research that revealing eating habits is characterized by high expectations for eating behaviors, and at the same time very sensitive to food warnings, which can promote healthier eating behaviors.

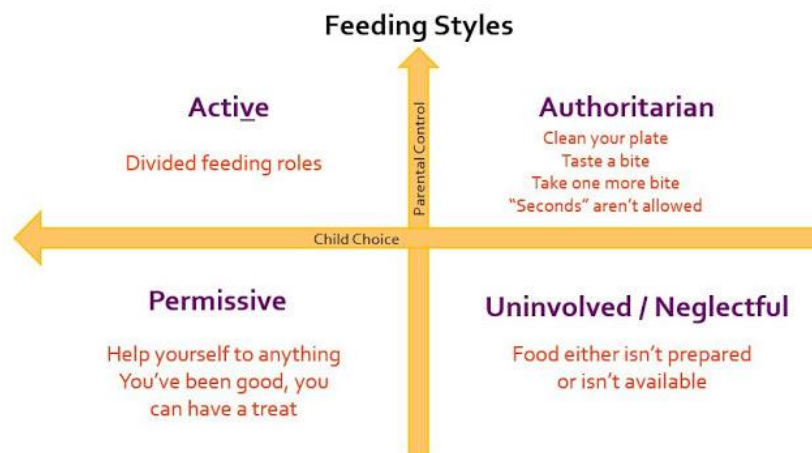


Figure 5: Feeding Styles

The limitation and the pressure to eat used in the authoritarian feeding style weakens the child's natural hunger and full cues, according to *Satter*⁷⁰, *Hughes*⁷² and *Birch*.⁷³ They will frequently eat more restricted food when they have access and overall have lower positive feelings about food

and eating. Permissive feeding leads to trouble self-regulating intake and often creates a relationship between food and love. Uninvolved feeding leads to overeating when food is available.⁷⁰ As a result, these feeding styles result in higher weights in comparison to the families where feeding roles are divided, as seen in figure 5.⁷¹



Figure 6: Division of Responsibility in Feeding

The objective in feeding is to raise competent eaters. A competent eater has positive feelings all around eating, eating food they enjoy and eating enough to feel satisfied, according to *Ellyn Satter*.⁷⁰ Her Division Of feeding Roles (*DOR*) are the benchmark used by registered dietitians (*RDs*) and child development experts as they help grow competent eaters, as seen in figure 6 and 7.⁷¹

The *DOR* breaks down the feeding relationship between parent and child and allows the child to take the lead and follow his/her natural ability to eat and grow in a way that is right for him/her. The concept behind the *DOR* is simple: In infancy: parents determine what the child eats (*breastmilk or formula*), while the child determines the where, when, and how much. As your baby transitions to solid foods: parents determine what the child eats as well the when and where, while the child determines how much to eat and even whether to eat the food that is offered.



Figure 7: Division of Feeding

The Current State of Diets of Typically Growing Children

Despite the available information on various parenting & feeding styles, there still seems to be a gap between the research and practices seen in general population. It is unsure what attitudes or beliefs of parents cause the child's undesirable dietary behavior and incorrect dietary intake.

Throughout human history, inadequate nutrition and food scarcity have been major threats to children's survival, and parental feeding practices have evolved in response to these threats. These feeding practices, which include behaviors such as providing large portions of edible foods and encouraging children to eat, are still inescapable in most cultures, despite the fact that in many regions the balance has shifted from food scarcity to food abundance and over-consumption has become a new threat.⁷⁴ The impact of these continuing practices on children's dietary intake can be seen in several recent dietary surveys.

The Feeding Infants and Toddlers Study (*FITS*), which supplied data on the dietary patterns of 3022 infants and toddlers, discovered that 4 to 24 month old children typically consumed significant quantities of developmentally inappropriate, energy-dense, nutrient poor foods.⁷⁵ A particular concern was the finding that 18% to 33% of infants and toddlers consumed no distinct servings of vegetables on a typical day and where vegetables were consumed the most common

option was French Fries. Moreover, reported energy intakes exceeded requirements by 10 to 30%.⁷⁶ Unfortunately, there is also evidence to indicate these patterns tend to persist throughout childhood and into adolescence, and that diet quality tracks and declines from early childhood through adolescence.^{77,78} Canadian Community Health Survey (*CCHS*) suggests that seven out of ten children aged 4 to 8 years fail to meet the minimum number of servings for vegetables and fruit in Canada's Food Guide to Healthy Eating.⁷⁹ These children also fall short of reaching the recommended servings for grains and milk products, implying that poor eating habits among children are widespread.

The transition into late childhood and adolescence can also be characterized by undesirable changes in eating behaviors such as increased consumption of sweetened beverages (*e.g., soda*)⁷⁷, calorie-dense, nutrient poor snacks⁸⁰ and food not prepared at home (*e.g., fast food*)⁸¹ and a decline in the consumption of milk and other nutrient-dense foods.⁸² Meal patterns also tend to change, as teenagers are more likely to skip breakfast⁷⁷ and less likely to participate in family dinners.⁸³ All of these tendencies are associated with decreased diet quality^{78,83} and may partly explain the fact that most adolescents are failing to meet the vast majority of dietary recommendations.⁸⁰

Parents as Providers, Models, and Regulators

It is clear from the literature that parents influence children's eating habits in different ways: parents actively choose family food choices as role models for nutritional decisions and patterns, and use feeding methods to highlight the development of diet and behavior patterns. Being a parent is also affected by the personality characteristics of the child, including age, gender, weight, and eating habits.^{81,84} This is how parents and children influence each other's eating behavior and react to each other. In addition, the practice of raising children is usually a response to the parents' threats to the health and growth of their children.⁸⁰ Regarding the food that parents

choose for their children, FITS research⁷⁵ shows that the "*Bigger is Better*" mentality will also affect parents' eating habits in terms of portion size and density. The energy of food for infants and young children. This will increase the child's overall energy expenditure. FITS parents report that they provide a lot of high-calorie foods⁷⁶ which can have a negative impact on children's eating habits and weight.⁸⁵ Several studies examining the effect of portion size on children's eating behaviors have shown that these are positively correlated with increased energy intake and weight.^{85,86} Children also learn to eat by observing the eating behaviors imitated by others. For example, studies have shown that children's consumption of fruits, vegetables, and milk has increased after observing adult consumption of these foods.⁸⁷ When children observe the eating behavior of their peers, the effect is similar: the choice and consumption of vegetables increases.⁸⁷ Therefore, active social modeling is an indirect but effective approach to support healthier diets for children.

Parents who are worried about their children's nutrition may try to reduce their diet, force their children to eat healthier foods, or encourage their children to eat healthier foods-these family customs may have unintended consequences.⁸⁸ Children's access to and consumption of delicious foods may lead to their preference or overeating if these foods are readily available.⁸⁸ Research also shows that encouraging or forcing children to eat more fruits and vegetables is associated with fewer fruits and vegetables⁸⁹ and higher dietary fat intake.⁹⁰ In addition, food rewards can also have unintended consequences, because rewarding children for eating healthy foods actually reduces attachment to these foods. These results indicate that regardless of parents' reasons to control their children's eating habits, over-steer will have an adverse effect on children's food intake and weight. Some children may experience eating disorders. Random eating is used to describe various irregular eating habits that may or may not guarantee a clear diagnosis of a

particular eating disorder. Diagnosed with “*Other Specific Food or Eating Disorders (OSFED)*”. The term “*Eating Disorder*” is a descriptive term, not a diagnosis. Therefore, although many people with eating disorders meet the EDNOS criteria, they may also have eating disorders that do not meet the current diagnostic restrictions for eating disorders. However, undiagnosed nutritional problems deserve attention and treatment because they can escalate into more serious eating disorders and expose people to serious health problems. An impaired diet may not have all the typical symptoms of an eating disorder. It is important to remember that even a person with irregular eating habits and behaviors can experience tremendous physical, emotional, and mental stress.⁹¹ In terms of parenting methods, authoritarian eating habits, that is, children's nutritional needs are high, and their sensitivity is low, leading to overeating, obesity, refusal to eat, and picky eating.⁷² In contrast, authoritative eating habits, such as strong pressure on eating habits while being sensitive to food cues, can encourage healthier eating habits.⁹² Coupled with the understanding of the impact of parenting patterns on children’s eating habits, there is strong evidence that the more acceptable “*Do as I Do*” method is more effective for children’s consumption than the unresponsive “*Do as I Say*” method. Birch et al⁸⁰ recommended several items for parents and guardians, including early avoidance and mediation efforts in general parenting, as shown in Table 2.

General guidelines for parents with feeding their typical children

Table 2: Guidelines for parents with feeding

- For the first 6 months of life encourage breastfeeding as much as possible.
- Build a “*flavor bridge*” for your baby during pregnancy and breastfeeding by diversifying diet and changing different diets for adults.

- Practice reactive parenting with the aid of using distinguishing starvation from different misery indicators and warding off with the aid of using usually the usage of meals to consolation your child
- To encourage people to accept and prefer these foods, you should be actively and repeatedly exposed to new foods (*especially foods that are often rejected, such as vegetables*).
- When changing to solid foods, please provide your children with healthy foods suitable for their development.
- Serve sized quantities which might be developmentally appropriate in your kid's age and nutrient needs
- Choose the time and food your child should eat, but let the child decide how much
- Trust a regular weight infant reputation to self-adjust his personal consumption
- Provide your child with a variety of easy-to-obtain nutrient-rich foods instead of high-calorie, undernourished foods.
- To model healthy dietary pattern, use you your own behaviors and attitudes
- Initiate regular family meals to create a positive feeding environment

Dietary Restrictions as interventions in ASD

The impact of recent dietary interventions on ASD has become apparent. Understanding the potential physiological effects of nutritional interventions is important because people with ASA already have complex and demanding eating habits.¹⁷ Therefore, it is very important to study diets because they can also exacerbate the imbalance of the intestinal microbiota and gastrointestinal problems. In the literature, the most widely studied nutritional method is the “Gluten-Free/Casein-Free Diet (*GF/CFD*)”, “Ketogenic Diet (*KD*)”, “Specific Carbohydrate Diet (*SCD*)” and “Mediterranean Diet” (*MD*).

Gluten-Free/Casein-Free Diet (GF/CFD)

GF/CFD is one of ASD's dietary interventions. The feature of this diet is to give up all types of flour, such as wheat, oats, barley or rye, and baked goods such as bread, cakes, pasta, and grain baked goods. Eliminating casein means that dairy products do not enter the body: milk, including breast milk, butter, cheese, yogurt, ice-cream or cream. Studies of healthy people have shown that a gluten-free diet is associated with a decrease in the number of beneficial gut bacteria, the increase the number of original pathogens and have an immunosuppressive effect.^{93,94} For people suffering from ASD and elsewhere, if allergies or allergic intolerance are diagnosed, this diet can be recommended.⁹⁵ ASD reported conflicting results. There is no doubt that a number of clinical studies⁹⁶ are promoting the use of this diet to improve ASD symptoms, indicating that the GF/CF diet can reduce the content of peptides in the urine, improve behavior, and reduce gastrointestinal symptoms.⁹⁷ Although other related studies⁹⁸ intake of this unusual diet will reduce fiber intake, thereby exacerbating gastrointestinal problems, the evidence supporting or disproving GF/CF in ASD has been banned so far, and the amount, quality and limitations have been studied many times within in the literature.

Ketogenic Diet (KD)

KD is a high-fat, low-carbohydrate diet, effective for epilepsy patients who do not respond to anticonvulsants.⁹⁷ KD has been studied in various neurological diseases and has been suggested for the treatment of ASD. Prescribing KD for ASD sufferers has proven useful effects, especially in slight to mild cases, and there are a few reviews of development in signs of epilepsy and behavioral disorders.⁹⁹ The biological knowledge about the role of KD comes from animal experiments. In the BTBR T + Itpr3^{tf}/J (BTBR) ASD mouse model, KD has been shown to boost ASD activity deficits (such as social skills, repetitive behaviors, and social communication).¹⁰⁰

Treatment of KD, mice with BTBR also improved the typical ASD defects associated with myelination and white matter development/connection by acting on neurotransmitter signaling pathways such as glutamate, serotonin, synthase, nitric acid and dopamine.¹⁰¹ In addition, BTBR mice showed different gut microbiota characteristics from control mice.¹⁰² However, KD is associated with an increased risk of defects and inflammatory mitochondria, and its side effects such as constipation and reflux can aggravate the gastrointestinal comorbidities of ASD. Diet is not enough to verify the feasibility of KD as a remedy for the disease.⁹⁹

The Specific Carbohydrate Diet (SCD)

Specific carbohydrate diet (SCD) is another nutritional regimen used with ASD but there are few studies on this regimen. SCD is a diet plan developed for patients with celiac disease¹⁰³ in the 1930s, but it is also used to treat Crohn's disease, ulcerative colitis, diverticulitis and chronic diarrhea.¹⁰⁴ The aim is to relieve the signs and symptoms of malabsorption and save you the growth of pathogenic intestine microbiota. The food plan recommends simple sugars from fruits, a few greens and honey, even as the consumption of complicated carbohydrates is restricted due to the fact their digestion time is a whole lot longer than easy sugars, and might also additionally cause ingestion complications, meals waste turns into a hotbed of pathogenic bacteria. Further studies is wanted to in addition compare the usage of the SCD software in kids with ASD.

Parent's Attitudes and Beliefs and Children's Dietary Behavior Intake

Typical Children

Parental perception have an immense influence on children's food habits.¹⁰⁵ Studies^{106,107} have shown that the surrounding environment, and in particular the domestic (*family*) one, has on children's food habits/preferences and the development of their food behavior is very strong and influential. Literature on the topic is wide and projects several variables affecting this relationship.

Most of previous research¹⁰⁶ highlighted the effect of family income (*Perceived Barriers*) on food habits. In specific, high-income families can afford a healthier diet, characterized by a high intake of healthier options of fruit, vegetables, fish, and dairy products; further, they choose for their children, foods rich in protein, polyunsaturated fats, folic acid, calcium, and iron.¹⁰⁸ In contrast, low-income families consume, higher amounts of meat products, whole milk, fats, sugars, potatoes, and cereals, while the consumption of fruit and vegetables is lesser (*unaffordability*).¹⁰⁶ It is interesting to note that although in the low-income families there is a high rate of overweight and obese children,¹⁰⁹ recent studies have pointed out a reversal results in this trend.¹¹⁰ There may be 2 reasons for the same:

- (i) Higher the presence of parents during meals more is the association to a greater control over the food taken by their children.
- (ii) The possibility of meals planned at home is linked to low income in the families.^{111,112}

Education is another potential aspect affecting the food habits—along with income. Previous studies^{106,112} examining this relationship have pointed a positive effect of parental level of education on children's intake of healthy foods such as fruit, vegetables, and fish. Furthermore, parental level of education is directly proportional to children's intake of calcium, carbohydrates, proteins, fibers, folic acid, and vitamin A.^{106,113} To this credit, educated mothers provide a more balanced diet to their child¹¹⁰ compared to those less educated which tend to prefer an unhealthy diet richer in added sugars.¹⁰⁶

Healthier food habits are also associated in the culture of eating food at home.¹¹⁴ Common analogy, children's food habits are positively influenced by parental food behavior according to the cross sectional studies.^{115,116} For example, a parent's diet poor in fruit and vegetables will have direct influence on the child to eat lower amounts of these foods as highlighted by another observational

study.¹¹⁷ An exploratory study¹¹⁸ states that parent food habits, indeed, are used as models by children who may decide either to conform to, or distance from these models. The habit of eating food at home also allows to bring children closer (observant) to meal preparation, which is known to affect positively both: healthy food habits and physical activities as observed by observed in the results of a multifamily focus groups.¹¹⁸ The effects on the latter are enhanced when the whole family is involved according to few cross sectional studies.^{119–121}

Lastly, literature also acknowledges on how the parental awareness about the nutritional characteristics of foods influences children's food habits.¹²² More specifically, higher parental awareness (*Perceived Susceptibility and Threat*) about nutritional characteristics of food better and healthier will be child's food habits.¹²² Parental awareness of food nutritional characteristics, will certainly decreases the purchase and consumption of unhealthy salty snacks and soft drinks, and increase the expenditure in healthy fruits and vegetables.^{105,123,124}

Children with ASD

Children adapt to the caregivers for dietary behaviors, food likes/dislikes and consumption pattern are finally groomed by their feeding style. Furthermore, it is interesting to note that the mother's educational qualification, job and food management techniques along with the interest, food habits, attitudes, beliefs and knowledge directly influence and has an impact on the nutrient intakes of children.¹²⁵ Parents of children with ASD tend to more apprehensive about their child's food intake, dietary habits or mealtime behaviors, including inclination for certain textures, refusal to new foods and picky behavior that differs from that of normally developing children.¹²⁶ Though the behaviors and influence of primary caregivers (*Perceived Susceptibility and Threats*) are closely associated with childhood dietary intake, food habits/perceptions and behaviors, only a few studies^{43,126} have been undertaken in pre-school aged children with ASD. A Korean study¹²⁷

demonstrated that the food habits of primary caregiver were related to those of children with ASD in the age group of 6-12. The study further highlighted that high nutritional perception and nutritional knowledge of caregiver was related to balanced weight status of children with ASD. It was also observed that the energy intake of children with ASD were met as per the Korean Dietary reference value of caregivers whose nutritional knowledge score was high.¹²⁸

Nutrients like calcium, potassium, vitamin A and folate were found to be less than the reference value¹²⁷ in children with ASD in Korea, as they were also found to have low intake of fruits and vegetables. Primary caregivers influenced unhealthy eating behaviors such as overeating, more salt in the diet and fussy/picky eating.¹²⁷ Several factors, such as family members, family environment and schooling hours directly affect the dietary behavior in a child with ASD, but the mother's influence had the greatest effect of all of them in the eating perception.¹²⁹ Moreover, when the mother's food habits, attitudes and interest in the child's nutrition was in place then that influenced the child's dietary perceptions positively.¹³⁰ Lazarou in his study¹³¹ reported that when parents had better understanding of nutrition and food habits themselves then children had higher and healthy intakes and better eating behaviors.

Autism's Clinical Companions: Frequent Comorbidities with ASD

There are several co-occurring physical and mental health conditions associated with ASD³³ that are important for general pediatricians, general physicians, and non-specialists to be familiar with, since they provide major healthcare services for people with ASD. These include:

- **Feeding/eating challenges and Obesity:** The two most common feeding or eating disorders for pediatricians/clinicians to be mindful of in their patients with ASD are selective eating and obesity. Thirty percent of children with ASD are obese, compared with 13% of the normal

population. Sensory issues, anxiety, side effects of medication, isolation from society, and activity level can all be associating and underlying factors.³³

- **Epilepsy/Seizures:** Epilepsy³⁴ is seen in a remarkable 25% to 40% of individuals with ASD, compared to 2% to 3% of the general population, and seizures are a major symptoms which are of concern for families. Research found intellectual delay, an underlying neurologic disability, family history of epilepsy, and severe cognitive delay/abnormality increase the risk of epilepsy in patients with ASD.³⁴

Symptoms to inquire with parents include constant/repeated, unexplained abrupt/quick changes in behavior such as staring spells, muscle stiffening, involuntary movements/jerking of limbs, or sudden sleepiness or sleep issues. Others might be unalarmed, random, unexplained, and significant irritability or aggression, or retreat in normal development.

- **Sleep disorders/disturbance:** Anywhere from 50% to 80% of children with autism suffer with chronic sleep issues — and so, their parents. Problems may include but not limit to difficulty in sleeping, frequent waking, and prolonged time of keeping awake, or rising very early. Sleep issues are closely related to daytime behaviors and thus affect the life quality for the entire family. Sleep could be affected by genetics, medication, and anxiety. Common interventions with sleep hygiene can help, and experts have put together parent-guided programs to support/help improve sleep issues in children with ASD.³⁵
- **ADHD, Anxiety, Depression:** Psychiatric comorbidity of some form is seen in as many as 85% of children³⁵ with autism, and 35% are taking treatment with at least 1 psychotropic medication. The most common diagnosed comorbidity seen are ADHD, anxiety, and depression, with anxiety and depression being particularly high and so it is important to watch for in teenage children, as they become more self-aware/self-conscious.¹³²

ADHD can be extremely tricky and difficult to distinguish from ASD, even for trained and experienced clinicians, as the core symptoms of ASD could look like attention problems or hyperactivity (*lack of eye contact, repetitive behaviors, etc.*).

- **Gastrointestinal disorders:** As many as 85% of patients with ASD experience GI disorders. Despite the high percentage, no known genetic or neurologic explanation has been linked to the occurrence of GI issues. Many children and adults with ASD are quite in discomfort, probably due to GI disorders.¹³³

Symptomatic behavioral clues that an individual may be experiencing (*pain*) related to GI problems (*diarrhea, constipation, gaseousness, or painful bowel movements*) include arching the back, pressing the belly, or gritting teeth. Patients with GERD might strain the neck, hold the jaw out, tap the throat, will not lie down, experience lack of sound sleep, or deny food. It may take some probing to find the root cause of GI problems in individuals with ASD, since many have special or restricted diets due to oral sensory issues or parental choice (*gluten- and casein-free*).¹³² In some cases, medication may be causing GI side effects.

These issues can last lifetime but may also disappear or diminish at different stages of life. Shockingly, various studies show that individuals with ASD have remarkably shorter lifespans not due to the condition (autism) itself, but due to co-occurring mental and physical health conditions.

Diagnosis of comorbidities may be challenging as most people with ASD have difficulty identifying and revealing their symptoms. Physical discomfort might promote spikes or incidences in self-soothing constant behaviors as well as irritable, aggressive, self-injurious, and other challenging behavioral issues. That makes it challenging to differentiate out whether the unusual behaviors are connected to ASD or to physical discomfort because of co-occurring condition.

Feeding guidelines for children with feeding difficulties

Researchers in their study^{135,136} have done clinical investigations systematically and have listed some viable practical approaches to manage feeding in children with feeding issues. Thus, following are the basic feeding principles for children with feeding difficulties:

1. Boundaries should be maintained appropriately.
2. A child-size chair at the table should be used and all kinds of distraction (*e.g., television viewing, games, cell phones, toys, and books*) or noise should be avoided.
3. Avoid snacks and beverages between meals to promote and maximize appetite, Feeding should be only at intervals of 3–4 hours.
4. Anxiety, anger, and excitement should not be revealed ever at mealtime. Only keep an ever-smiling face and a neutral pleasant attitude.
5. Mealtime duration should not be longer than 20–30 minutes
6. Use only small helping sizes and serve age suitable foods to suit the child's oral motor development.
7. Introduce one new food at a time and systematically, and offer a food repeatedly, at least 5 to 15 times, before trying another one or giving up.
8. Toddlers should be encouraged to feed themselves using a spoon or a fork.
9. Let the child make a mess while feeding on his/her own during mealtimes. Do not keep wiping every time in between child's eating or drinking.

Role of Dietitian, Therapist and Physician

Once a child is diagnosed with ASD and has feeding difficulties, the physician refers the child to a team of therapists and dietitians. The team of healthcare professionals work in conjunction with each other with a primary goal of feeding therapy, *i.e.* to help parents develop a normal, effective

feeding patterns and behaviors in their child. The therapists work in close proximity with the children and their immediate families and caregiver to detect the source of the child's difficulties and develop a game plan with specific therapies to make the entire eating process easier and more enjoyable. The skills taught to a child is very basic and are determined based on his/her needs and thus will differ from child to child. The most common skills taught¹³⁵ to these children are:

1. Oral Skills – Therapists teach the skills required to eat or drink, due to delay in development. Further on, the therapists work with the children to teach them additional skills on how to control and coordinate chewing, sipping from a cup, sucking, and swallowing while eating and drinking simultaneously. They also work with the children to increase each child's oral strength/durability and motion range.
2. Food Orientation – Therapists also work with children and their families to increase the intake and variety of foods the child is ready to eat. Most children, more so those with sensory aversion issues, or those who have had a very limited awareness/exposure to a variety of foods, may be taught and guided with skills on how to minimize their sensitivities to food and their textures.

Therapists also teach and assist with patients to help them get the self-feeding independence¹³⁷ that many of them desire, by teaching basic skills like drinking from a cup, using a spoon or fork to eat or drinking using a straw. By teaching the child basic skills of feeding and how to reduce mealtime unpleasant behaviors and retraining the child's parent/caregiver on how to indulge in a positive mealtime experience, meals and snacks may become easier and enjoyable for the entire family.

Nutrition is not one size fits all! The dietitian will evaluate and assess diet, health, and nutritional concerns on an individual level using the most current evidence-based research. In addition, they are mindful of the unique health and behavior concerns that may be present with autism. The

experts will create a customized plan to help improve the child's nutrition in a way that works for the family. The dietitian will educate on a lifestyle that is sustainable for the child with selective eating and behaviors. They will execute the following:

- Assess and evaluate dietary intake and health status.
- Determine where potential nutrient deficiencies may exist.
- Identify if there is adequate energy or calorie intake to support growth and development.
- Educate on serving size and food group recommendations for the child's age and specific situation.
- Assist with the implementation of doctor-recommended dietary interventions.
- Provide tips on increasing food acceptance and quality of nutrition.
- Assist with physical activity recommendations and plans.

Statement of the Problem

Some characteristics specific to autism such as hypersensitivity to sensation (touch) and behavioral stubbornness that instigate individuals to deny novel experiences are shadowed in the attitudes of food denial and food selection in children with ASD.^{17,136,137} In addition to the specific characters of ASD that may lead to restrictive dietary behavior, *Curtin et al*¹³⁸ indicates that children with ASD who choose to be highly restrictive in terms of what they will or will not eat, have more behavioral issues at mealtimes, subsequently creating higher conjugal stress for their parents. The occurrence of severe behavioral issues in children with ASD was shown to increase the possibility of the parents suffering from symptoms of anxiety/depression. Conversely, evidence also indicate that parental behavior may equally affect the course of autism from the child's early years until adulthood.^{139,140} Within this background, in order to better understand the eating behavior/problems of the child with ASD, not only the specific characteristics of ASD must be taken into consideration, but also the parents' attitude and behavior in relation to the child's dietary restrictions and preferences. *Skinner et al*¹⁴¹ examined children's food preferences/choices and inferred that the mothers with held their children with foods that they themselves disliked, and that the children were more than likely to not reject the food that their mothers enjoyed the most.

Some mothers favor faster to their children's food demands and make many exclusions, catering and letting them choose the food they what to eat. This favoring attitude appears to be justified by the mother's belief that the dietary habits of children with ASD are very selective and very restrictive. According to *Birch*,⁷³ when given the chance to choose, our genetic predisposition induces us to reject anything that is unfamiliar. Added to that there is a tendency to choose foods that taste sweet or salty, foods that are part of a social context and foods, when consumed, are supported by a positive sensation, e.g., dense-energy foods consumed when a person is hungry.⁷³

Thus to conclude, food choices are part of the arsenal of every individual human being and every child, but can be mis-interpreted with the specific selectivity of autism. At the same time, guarded by ASD, parents may get dejected or fore go on their attempts to stipulate a more stricter dietary education and give in to their children's demands.

Children use inappropriate behavior as a strategy to ensure that they get their way to eating their desired and reject anything of their dislike or something they are not familiar with. With the fear the mother has that the child may not eat anything pushes her to succumb to the child to eat anything at all or even give in to him/her to eat anything that the mother believes he/she will like. Thus, depending on the child's demands and the attitudes of the family, a repetitive loop may be defined with regards to the dynamics of food intake. In the first take, the food demanded by the child (*or the food that the child's parents suppose will please him/her*) is offered instantly and used as a bargaining tactic. Subsequently, the child consistently refuses any food that is not in the list of his/her likes so that the main meals (*lunch and dinner*) are substituted with snacks with very less nutritional value. A restricted diet is then in place, the contents of which were demanded by the communication between the attitudes and behavior of the child and those of the family with respect to food intake. During this process, the child begins to play games and add pressure to get specific foods by crying with insistence constantly, self-mutilating and screaming if the child has not mastered speech. In a study¹⁴² it was inferred that the children's attitude reversed completely when they were by themselves with their father, suggesting the possibility that the person/caretaker taking care of the child is encouraging the unwarranted eating behavior. Some studies indicate that the anxiety prevails in the mothers of individuals with ASD and it is very high which could be contributing to more permissive behaviors with respect to the children's demands rather than adhering to a more educational approach, even with respect to dietary knowledge.^{143–145}

To sum it up, it is evident from literature that parenting and feeding styles along with parent involvement (*Providers, Role Models and Regulators*) has an impact over the child's eating behavior and intake irrespective of their condition (*Typical or ASD*). It is also evident from several studies done, that parent's nutrition perception and nutrition knowledge have positive effect on children's dietary behavior and their dietary intake, irrespective of whether the child under the spectrum or a typically growing child. Most nutrient intake of these children, whose parents have high nutritional knowledge, are at moderation. However, calcium potassium, vit A & folate seems to be lower than the reference value. Most of these studies with children under the spectrum were conducted in East Asia. (*Korea, China, and Japan*) in the age group of interest of the present study. There is not much evidence from literature that has assessed parent's attitudes and beliefs in the US for children with ASD in the age group of 5-13. Thus, this study is warranted to assess parent's attitudes and beliefs of children with ASD with respect to their dietary behavior using a Health Belief Model. This cross-sectional descriptive study will assess the relationship between parent's perceived barriers and self-efficacy with their child's dietary behavior. With the emerging popularity of GF/CFD's in this population, it is possible that these children may lack calcium, dietary fiber, vit D and calories. Thus, the study will also assess parent's attitudes and beliefs with respect to dietary fiber, calcium, vitamin D and calorie intake.

Theoretical Framework

The Health Belief Model

The Health Belief model (*HBM*) is a conceptual framework, which would be used for guiding parents with healthy eating habits and combats the co-occurring or the co-morbidities along with the existing condition of Special Needs (*ASD, ADHD and Asperger's*). This model is chosen, as it is most popularly used conceptual framework for explaining, elucidating. predicting and an

influential factor for health-related behavior and has received great constant support from both prospective and retrospective studies.¹⁴⁶ Key elements of the HBM focuses on the beliefs of parents'/guardians' understanding about health conditions which would possibly predict their health-related behaviors. The predicted ability of the parents/caregivers would vary depending on their ability to gauge the presence of perceived susceptibility, severity, benefits of action, barriers of action and the sense of self-efficacy of the targeted population. Programs involving parents based on models with social learning have been studied extensively in many studies and have been shown to be promising in promoting positive changes in both parent and child behaviors.¹⁴⁷ In specifics, they are one of the best evidence-based solutions for children and young adults with problems like disruptive behaviors and ADHD.^{147,148} Though parent involvement is increasing, there is little research that has been done on testing factors related to involving the parents in interventions with parenting. There is a dearth of research based by a theoretical framework, as most present studies have based on variables of convenience.¹⁴⁹ This study will therefore provide an important novel application of HBM and the rationale for using HBM is as follows:

- **Perceived Susceptibility:** This refers to an assessment of risk of developing health problems with unmanaged co-occurring symptoms subjectively.¹⁵⁰ According to HBM model parents are more likely to involve in a positive behavior in terms of diet, activities, and therapies only if they feel that their child is vulnerable to developing behavioral problems in the future. For this positive behavior to occur in parents, they must be informed about the condition and associated problems with the condition if not attended early on. Knowledge about their child's condition and possible consequences will alarm the parents to adapt to positive behavior towards their child's diet and lifestyle.

Parents/Guardians with low perceived susceptibility may deny that their child is at a risk of contracting any major health issues. Some others may even acknowledge the possibility that their child could develop some severe health conditions, but believe it is very unlikely. These set of parents who believe that their child is at an exceptionally low risk of developing any complications or disease conditions on a later date with the co-occurring symptoms, are more likely to engage in unhealthy eating and lifestyle. Parents/Guardians who do perceive a high risk of developing any major health conditions as an adult, would engage in seeking help and following guidelines to give their child a healthy growing. This is more with the fear, that the parents/guardians realize that as even as an adult, their child, maybe dependent on them for their day-to-day living.

- **Perceived Severity:** This refers to the assessment of the severity of a problem with health and its consequences.¹⁵¹ The HBM proposes that parents/guardians who perceive co-occurring symptoms in special needs, to be a condition of a serious nature, are more likely to engage in giving their child necessary attention to healthy living. This is more so, because the parents/guardians believe that by decreasing the co-occurring symptoms will probably delay or quash a chance of developing any major health conditions. This way the child will also get relief and will be able to lead a close to normal life.

The combination of severity and susceptibility maybe a threat. If the parent/guardian has enough knowledge and awareness of what complications the child may face on a later date as an adult, if the co-occurring symptoms are not addressed at the very beginning, then, the parents/guardians would take keen interest in decreasing the co-occurring symptoms in which ever healthy way possible.

- **Perceived Benefits:** Health-related behaviors are also affected by the perceived benefits of taking action.¹⁵² The perceived benefits refer to an individual's understanding about the complications, severity of the conditions and what they have read or heard from their friends and family. If the parent/guardian has heard from their friends with similar conditioned child about a diet or supplement which may have benefitted them then these parents would want to follow the same regimen irrespective of easy availability and convenience to try it. If a parent hears about gluten-casein free diet or benefits of probiotics, then they would surely want to try it for their child.
- **Perceived Barriers:** Health-related behaviors are also an action of perceived barriers to acting. It is an individual's evaluation of the adversity to behavior change.^{153,154} Even if the parent/guardian perceives the co-occurring symptoms to be threatening and believes that a healthy food choice or therapy will reduce the threat effectively, barriers may stop engagement in these health promoting behaviors. The barriers could be financial, situational or social aspects. For instance, a parent/guardian may not be able to afford fresh foods and vegetables and may not receive any public food assistance, or the parent may work long hours and not have time to cook fresh and healthy.
- **Self-Efficacy:** This refers to an individual's perception of his/her ability to successfully conduct a behavior.¹⁵⁵ The parent/guardian needs constant re-assurance that they are doing a good job rearing their child. This would give them a boost to try and continue to work with their children, to decrease their child's co-occurring symptoms. Thus, support from home, workplace, school and society will make an impact on the parent's/guardian's attitude towards working to decrease their child's co-occurring symptoms and thus decreasing the chance of developing any severe health conditions later.

Conceptual Framework

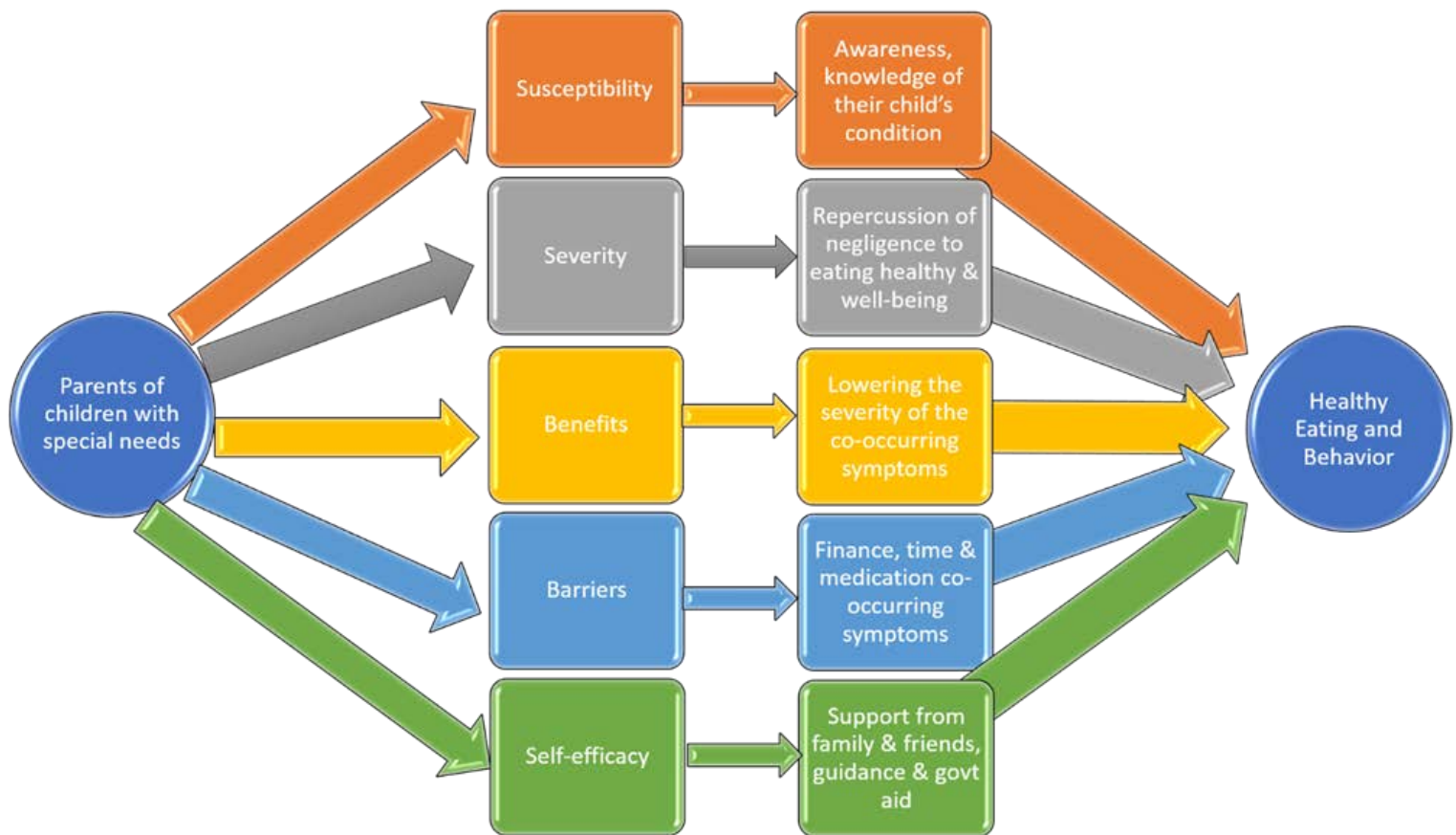


Figure 8: Healthy Eating and Behavior

According to this HBM model, parents are more likely to involve in a positive behavior, in terms of their diet, activities and therapies, only if they feel that their child is susceptible to developing behavioral problems in the future. (*Perceived Susceptibility*). Parents, if believed, that those problems will have a highly negative impact, then behavior towards their child's well-being will be positive (*Perceived Severity*). If parents perceive that healthy eating (*including food from all groups*) will be effective in reducing the risk of behavioral problems in their children, (*Perceived Benefits*), then, their attitudes would be of a positive nature. If parents find do following steps to healthy living too demanding, in terms of finance, time and practicality, they will falter from practicing a healthy living lifestyle (*Perceived Barriers*). If parents feel confident, that with

the support of family and friends, guidance from professionals from the field will be able to work with their child's dietary intake and behavior, then they would show positive health behavior. (*Perceived Self-Efficacy*). All the discussed constructs are as seen in figure 8.

Research Aims

The overall aim for this project was to examine the relationship between parents' attitudes and beliefs towards their ASD children and the children's dietary behaviors. The specific aims for this research project were:

Primary Research Aims:

1. Aim 1: To describe the diet quality of children with autism using Healthy Eating Index (HEI) scores
Hypothesis: HEI score will be lower in children with autism as compared to their counterparts in the age group of 5-13 years.
2. Aim 2: To Assess the relationship between parents' perceived barriers and children's dietary behaviors.
Hypothesis: Higher parent perceived barriers will be negatively associated with child's dietary behavior score assessed by Brief Autism Mealtime Behavior Inventory (BAMBI)
3. Aim 3: To Assess the relationship between parents' self-efficacy and children's dietary behaviors.
Hypothesis: Higher parent self-efficacy will be positively associated with child's dietary behavior score assessed by Brief Autism Mealtime Behavior Inventory (BAMBI).
4. Aim 4: To Assess the relationship between parents' perceived barriers and children's calorie, dietary fiber, calcium and vitamin D intakes.
Hypothesis: Higher parent perceived barriers will be associated with inadequate intakes of calorie, dietary fiber, calcium and vitamin D.
5. Aim 5: To Assess the relationship between parents' self-efficacy and children's calorie, dietary fiber, calcium and vitamin D intakes.

Hypothesis: Higher parent self-efficacy will be associated with adequate intakes of calorie, dietary fiber, calcium and vitamin D.

An exploratory analysis was conducted to assess the relationship between constructs of perceived susceptibility, benefits with children's dietary behaviors, as secondary aims to this study. The secondary aims also looked at the effect of dietary intake (*fiber, moisture, HEI and GF/CF diet*) on gastrointestinal systems. It also explored the difference in dietary intake between children consuming GF/CF and regular diets. The study also looked at the effect of dietary intake on BMI of the study participants.

Secondary Aims:

1. To assess the relationship between parents' perceived susceptibility and children's dietary behaviors
2. To assess the relationship between parents' perceived severity and children's dietary behaviors
3. To assess the relationship between parents' perceived benefits and children's dietary behaviors
4. To assess the relationship between dietary intake and gastrointestinal symptoms
5. To assess the relationship between dietary intake and GF/CF diets.
6. To assess the relationship between dietary behavior and BMI

Methodology

Study Design

A cross-sectional study of descriptive nature was conducted to assess attitudes and beliefs of parents towards their children with special needs and how these attitudes and beliefs may be associated with dietary intake and diet-related behaviors. Data about children's behavior during mealtime as well as parents' or caregivers' beliefs and attitudes towards their children's dietary behavior were collected via a self-administered online questionnaire or by principle investigator

filling out the surveys on behalf of the participants with their inputs over a telephonic interview. Dietary intake data corresponding to one weekday and one weekend day were collected by phone interviews conducted with parents or caregivers.

Study participants and inclusion criteria

Children with a diagnosis of autism, aged between 5 and 13 years were recruited for this study between October 2020 and March 2021. The diagnosis of the participants was determined by their Individualized Educational Plan (*IEP*), which school authorities had on record, for children who participated through schools. For children who participated through other means, their diagnosis was ascertained by their support groups, therapists or their parents and caregivers.

Although parent involvement of children with autism is from infancy to onwards,^{156,157} schooling age of elementary schools in the ESE program ranged between 5 and 13 years. Children with ASD under the age of 5, fall under the individual family service plans (*IFSPs*). Through this program children in their toddler years can avail several services like *Early Intervention*, *Government Aids like WIC, etc.*, where they and their family are served. They may not have issues as compared to older children who are beyond the service age cut-off. Hence, we may not get a true picture of the issues, parents/caregivers may face. Thus, the afore mentioned reasons are the rational for selecting the age group 5-13 years. The dependency of a parent by these children may vary depending on the severity of their condition. Another inclusion criterion was that the child with autism should consume solid foods orally and not be on any enteral or parenteral feeding.

Private elementary schools (*'Jax School for Autism'*, *'Little Star Center'*, *'North Florida School of Special Education'*) primarily in the North Florida Region who provide the Exceptional Student Education (*ESE*) program were approached for distribution of flyers about the study. Some participants attending public school were recruited by the principal investigator's personal contacts

through email and WHATSAPP. Participants were also reached via support groups (*'Pure Hearts of Georgia (GA)'*, *'A Broader Spectrum of Therapies (PA)'*, *'A Mother's Rest Charitable Respite Foundation (MD)'*) and, through a snowball sampling method, a wider audience was recruited from all over the USA including Autism-focused organizations such *'Autism Speaks'*, *'Autism Society of America'*, *'Autistic Self-Advocacy Network'*, *'Autism Research Institute'*, *'Autism Science Foundation'*, and the *'Autism National Committee'*. Participants were also recruited from India through a support group named *'Forum for Autism'* where snowball sampling method was used to recruit 30 participants. Once the parent contacted the principal investigator via email or phone, as indicated in the flyer, a link was sent to them for their consent along with study instructions, available on an online survey website. Upon consenting to participate in the study, the parents were provided with an individual Qualtrics link and prompted to answer Demographic questions (*Appendix B*), Nutrition and Health Awareness Questions (*Appendix C*), BAMBI Questionnaire (*Appendix D*). The parents were then contacted by phone at an agreeable time as indicated in the consent form (*Appendix A*) to record the 24-hour dietary recall for one weekday and one weekend day.

This study was approved by the Institutional Review Board at the University of North Florida and all participants provided a signed electronic consent form prior to participating in the study.

Data Collection

Consent Form (*Appendix A*)

A consent from the parent of the participant was acquired virtually in Qualtrics, before the actual survey questionnaire was presented to them online, through Qualtrics.

General Questionnaire and Pertinent Information (*Appendix B*)

The questionnaire survey was completed by participants either through self-reporting on the online survey in Qualtrics or via telephonic interviews between parents and the principle investigator.

Parents completed the questionnaire in which information regarding children's anthropometrics, gastrointestinal symptoms, sleep issues were obtained. This questionnaire also had parent's educational and employment status.

Nutrition and Health Awareness Questionnaire (*Appendix C*)

The Nutrition and Health Awareness Questionnaire is a 27-item questionnaire which has been adapted from among the validated questionnaires used in previous studies^{158,159} to measure the constructs of the Health Belief Model (*HBM*) of interest in this study. The questionnaire addresses the constructs of the HBM including parents' perceived susceptibility, severity, benefits, barriers and self-efficacy to positive feeding behaviors in their children. The questionnaire measured Perceived Susceptibility and Severity with questions 1-13, perceived barriers with questions 14-19, perceived benefits and self-efficacy with questions 20-27. All four constructs were measured using a 5-point Likert Scale where 1=Strongly Disagree, 2=Disagree, 3=Neutral, 4=Agree and 5=Strongly Agree. The score ranges from 27 to 135.

Brief Autism Mealtime Behavior Inventory (*BAMBI*) – (*Appendix D*)

BAMBI is a validated questionnaire specifically developed for children with autism.^{157,160,161} The questionnaire addresses the child's difficulties at the mealtime including foods offered, presentation, texture, smell and sitting at the table. The 18 items of the questionnaire are measured using a 5-point Likert Scale where 5=Always, 4=Often, 3=Occasionally, 2=Seldom and 1=Never. The score ranges from 18 to 90.

Dietary Recall (*Appendix E*)

Using the ASA24 Recall Tool¹⁶² (*NIH – National Cancer Institute*), the children’s dietary intake during one weekday and weekend day was recorded via interview with the parents. Online pictures were presented for some parents to easily determine the food type and portion size. Some parents chose to share pictures of the supplements that their child was consuming, which helped determine the nutrients in the supplements and add it to the ASA24 Recall. Extensive evidence has demonstrated the validity of 24-hour dietary recalls, which provide exceptional quality of dietary intake data with minimal bias, thus making it a reliable tool for policing the diets of populations and for studying relationships between diet and diseases.^{163,164}

Data Analysis

The sample size calculator by Qualtrics¹⁶⁵ was used to determine the ideal sample size for data collection. A minimum ideal sample size of 66 was determined as illustrated in table 3 below.

Table 3: Sample Size Calculation

Total Number of Public Elementary Students in Duval County ¹⁶⁶	80,560
Total Number of Private Elementary Students in Duval County ¹⁶⁷	25,970
Total Elementary Students in Duval County	106, 530
Special Needs Students in Duval County (1:54) ¹⁶⁸	1972
Confidence Level	90%
Margin of Error	10%
Ideal Sample Size	66

Prior to data analysis the data were reviewed for missing values but there were no missing data. The Nutrition & Health Awareness questionnaire and BAMBI questionnaire were imported into SPSS (*version 26*). Internal consistency for the factors in the questionnaire was checked by running a Cronbach’s α coefficient test on the responses.

All the nutrient values from the dietary recall were exported as an Excel spreadsheet to calculate the Healthy Eating Index (*HEI*) scores for the participants from India and the USA, separately. The HEI calculation was based on the 2015 Dietary Guidelines and comprised the

components namely: total fruit, whole fruit, total vegetables, dark green and orange vegetables and legumes, total grains, whole grains, meat and beans, milk, oils, sodium, saturated fat, and calories from solid fat, alcohol, and added sugar.¹⁶⁹ A score of up to 100 is possible where higher scores reflect higher diet quality. The reliability and validity of the HEI were established by the original authors¹⁷⁰. These scores were further used as a variable to determine the relationship between diet quality and GI symptoms.

Descriptive statistics were generated for all variables, where frequencies and percentages were calculated for the gender, age, parent's educational qualification, parent's employment status, sleep issues, GI issues and GF/CF diets, and means and standard deviations calculated for dietary nutrients, derived from the ASA24-hr recall tool.

Histograms were generated using the data from the constructs (*Perceived Susceptibility, Severity, Benefits, Barriers & Self-Efficacy*) and dietary behavior (*BAMBI*) to determine the distribution of the sample. Non-parametric tests were executed, as the distribution of the data was not normal.

Spearman's correlation coefficients were generated to determine the correlation between constructs of HBM with BAMBI and calorie intake, and BMI with calorie intake. Partial correlations were also generated between HBM constructs and BAMBI, factoring in age of participants.

Logistic regression models were constructed to determine the associations between dietary variables and the presence or absence of GI issues.

A Wilcoxon Rank Sum test was conducted to compare nutrient intake (*Calorie, Carbohydrates, Protein, Lipids, Moisture, Fiber*) between children who followed a GF/CF diet

versus those who did not. Data analysis was conducted using IBM SPSS version 26.0 software,¹⁷¹ and *P*-values lesser than 0.05 were considered significant statistically. A One-Sample T-test was performed to identify the difference in the medians of the observed HEI Score amongst participants from US with Autism and the national standard for HEI Score in typically growing children from the US.

Results

A total of 109 children participated in this study.

Table 4: Demographics, gastrointestinal symptoms and sleep status of children with autism

Participants Characteristics	N	%
Country		
USA	79	72%
India	30	28%
Sex		
Male	96	88%
Female	13	12%
Age Group		
Primary School	64	59%
Middle School	45	41%
Race		
African American	23	21%
Asian	43	39%
Caucasian	31	28%
Hispanic or Latino	12	11%
Other	0	0%
Parent Employment Status		
Employed	53	49%
Homemaker	35	32%
Unemployed	21	19%
Parent Education		
Graduates (<i>College 3yrs +</i>)	70	64%
Non-Graduates (<i>GED and below</i>)	39	36%
Sleep Issues		
Yes	54	50%
No	55	50%
GI Discomfort		
Yes	62	57%
No	47	43%
Special Diet		
Yes (<i>GF/CF^d</i>)	44	40%
No	65	60%

^d GF/CF - Gluten Free / Casein Free Diet

Table 4 presents descriptive statistics for participants' characteristics. It also gives general demographic information about the parents along with their educational and employment status. There were 79 participants from the US and 30 from India. There were more boys than girls in the study, as expected. However, the boys to girls ratio was higher than seen in earlier studies.¹⁷² The

majority of the population in this study were in the Primary age group with a mean age of 10 years. The population of the study was ethnically and geographically diverse. The states of residence reported by participants from India and the U.S. are illustrated below, in Figures 9 and 10, respectively. The survey was mostly taken by the mothers (90%) of the participants though there were few fathers (10%) who took the survey in this sample. Fifty percent of the population in the study had sleep issues. GI issues (*constipation*) were seen in 57% of the participants. Only 44% of the participants were on a GF/CF (*Gluten Free/Casein Free diet*). Cronbach's α coefficient was calculated to estimate the reliability in the General Questionnaire (α coefficients > 0.87) for the reported factors.

Table 5: BMI Percentile Analysis

BMI Percentile	Total	
	Girls (n=13)	Boys (n=96)
Min %	1	1
Max %	97.3	99.9
Median	83.2	95.6
Obese %	15.4	52.1
Overweight %	30.8	12.5
Normal %	38.5	22.9

Table 5 represents the BMI analysis for the study participants. The BMI percentiles ranged for 1 – 99%. Approximately 52% of the boys and 15.4% of girls were classified as obese, based on BMI percentiles.

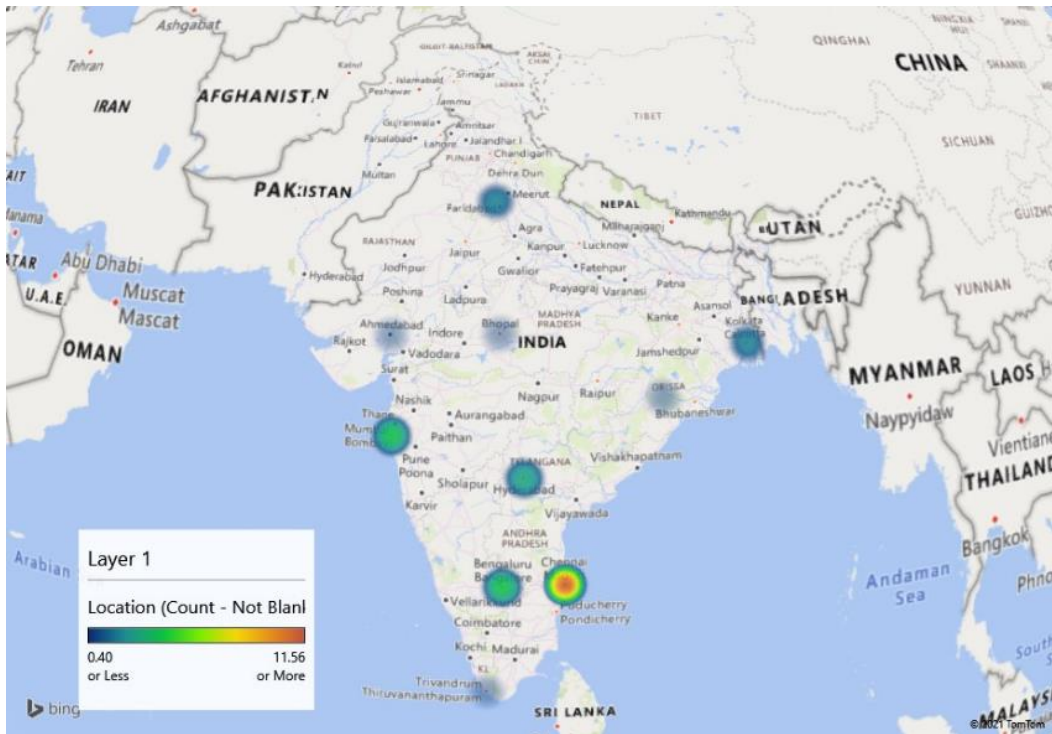


Figure 9: Map of Indian Participants

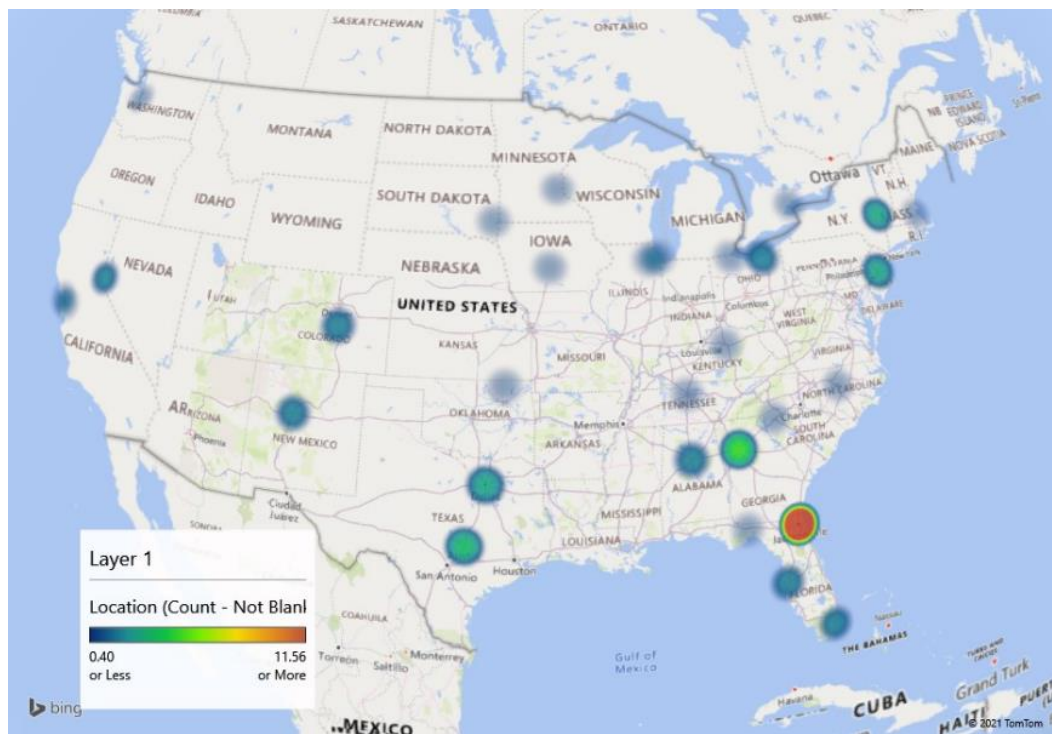


Figure 10: Map of USA Participants

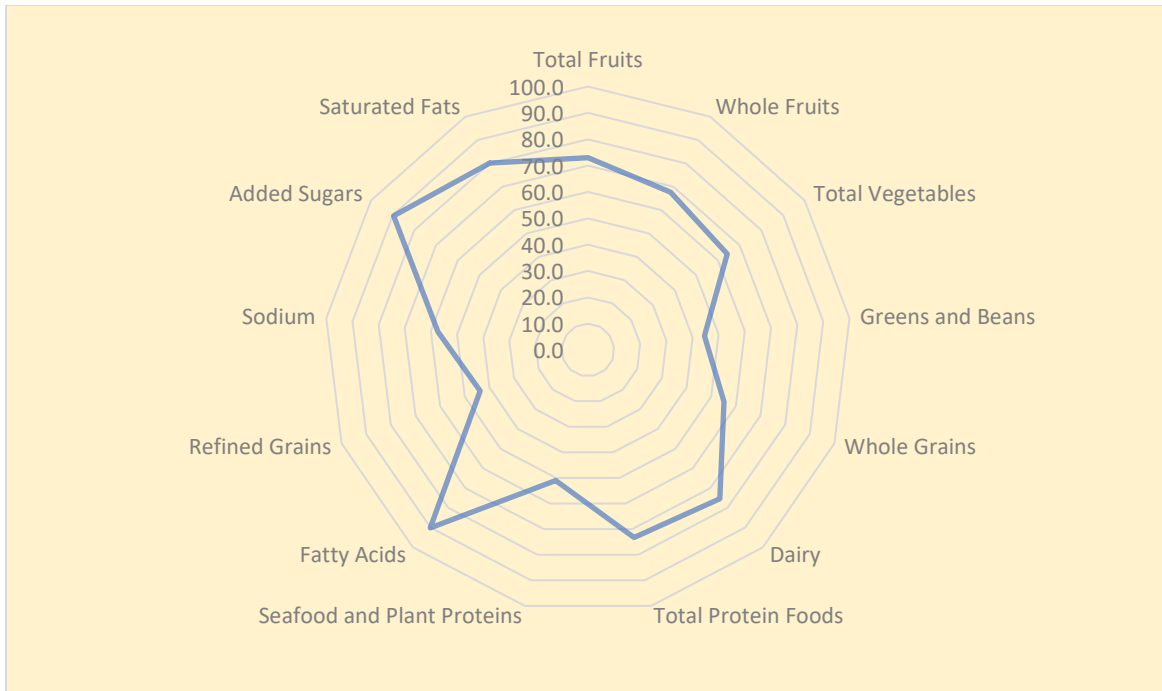


Figure 11: Radar plot of the components of the Healthy Eating Index (HEI) of Children ages 5-13 Diagnosed with Autism Spectrum Disorder for all participants.

Aim 1 of this study was to assess the diet quality of children with autism. Figure 11 represents the components of the Healthy Eating Index (HEI) of the study participants in a Radar Plot. The mean HEI Score for all participants was 69.8. In view of the striking differences in dietary habits between children living in the U.S. and India, separate radar plots were constructed for each group.

Figure 12 represents the HEI radar plot stratified by country of residence. The orange line corresponds to children in India ($N=30$) and the blue line corresponds to children living in the U.S. ($N=79$). The HEI scores for children living in the U.S. and India were 65 and 83, respectively. The HEI Score for the children living in the U.S. was compared with the HEI Score of a national sample of typically growing children ($HEI=53$), in the same age group of 5-13 years, using a one sample t-test. It was found that the HEI Score of typically growing children in the US was slightly lower ($M=53$, $SD=13.9$) than found in the study population with ASD, in the US, $t(78)=t7.6$, $p=0.00$.

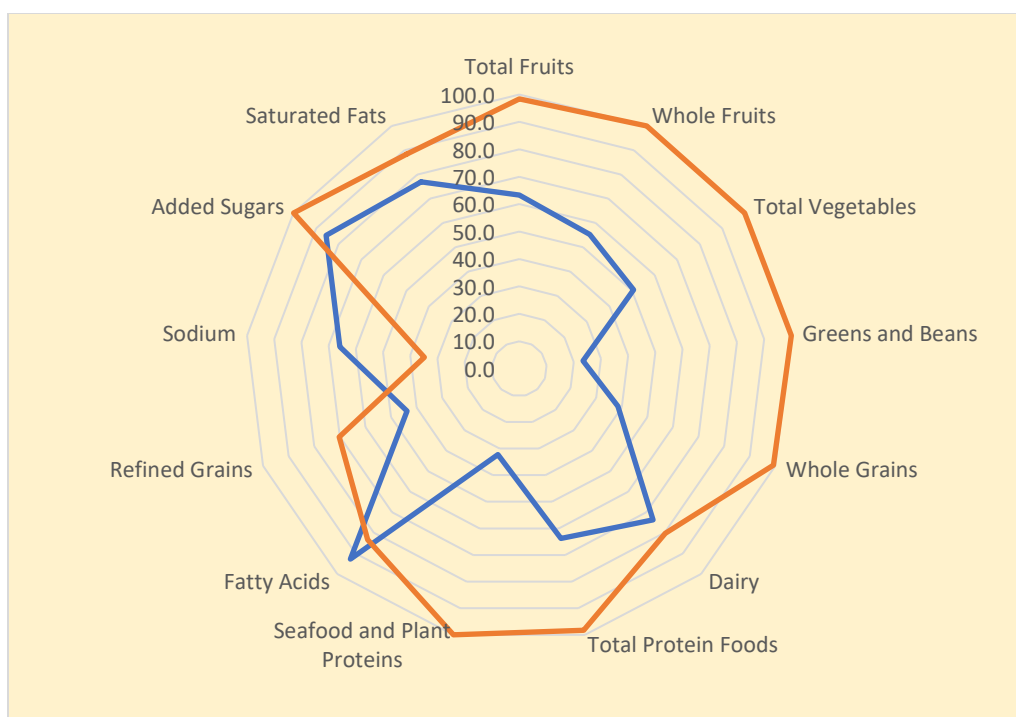


Figure 12: Radar plot of the components of the Healthy Eating Index (HEI) of Children ages 5-13 Diagnosed with Autism Spectrum Disorder from US & India

Table 6 presents the HEI scores for each component of the HEI. The table indicates that intakes of whole fruits, total vegetables, greens and beans, whole grains, total protein foods and seafood and plant proteins were inadequate.

Table 6: Healthy Eating Index Scores for all Components

	Maximum Score	HEI Scores
Adequacy:		
Total Fruits	5	3.6
Whole Fruits	5	3.4
Total Vegetables	5	3.2
Greens and Beans	5	2.2
Whole Grains	10	5.5
Dairy	10	7.5
Total Protein Foods	5	3.7
Seafood and Plant Proteins	5	2.5
Fatty Acids	10	9
Moderation:		
Refined Grains	10	6.3
Sodium	10	5.7
Added Sugars	10	9
Saturated Fats	10	8
HEI Score	100	69.8

Table 7: Spearman correlations between parents' perceived barriers, self-efficacy and dietary behavior of children with autism for all participants.

	<i>r_s</i>	<i>P</i> -value
Perceived Barriers & Dietary Behavior	-.794	<.001
Self-Efficacy and Dietary Behavior	.831	<.001

Aims 2 and 3 of this study were to assess the relationship between perceived barriers and self-efficacy with dietary behavior., Table 7 shows Spearman's correlations, adjusted for age. Cronbach's α coefficient was calculated to estimate the internal consistency of the reported factors in the Nutrition and Health Awareness and BAMBI questionnaires (α coefficients > 0.76).

Table 8: Daily intakes of energy and nutrients of children with autism, compared with the dietary reference intake (DRI)

Nutrients		DRI ^a (RNI or AI)	Median	Range	% ^b
Kcal	(4 – 8 yrs)	1747	1851.6	857.4 - 5240	106
	(9 – 13 yrs)	2200	2552.0	994.8 - 5165.3	116
Fiber (g)	(4 – 8 yrs)	25	16.2	8.5 - 59.1	65
	(9 – 13 yrs)	31	22.3	5.9 - 388.7	72
Ca (mg)	(4 – 8 yrs)	1000	959.4	298.6 - 1941.9	96
	(9 – 13 yrs)	1300	1064.4	481.7 - 2556.2	82
Vitamin D (mcg)	(4 – 8 yrs)	15	5.5	0 - 9.7	37
	(9 – 13 yrs)	15	5.1	0.1 - 17.5	34

^a National Institutes of Health – Office of Dietary Supplements. Nutrient Recommendations: Dietary Reference Intakes (DRI). https://ods.od.nih.gov/HealthInformation/Dietary_Reference_Intakes.aspx. Accessed on March 29, 2021. ^b Percentage of Median Intake over dietary reference intake (DRI)

Interest of nutrient intake in this study, namely calories, fiber, calcium and vitamin D, which was calculated from the two 24-hour recalls obtained, are presented in Table 8.

Table 9: Spearman correlations between parents' perceived barriers, self-efficacy and nutrient intake of children with autism for all participants.

	<i>r_s</i>	<i>P</i> -value
Perceived Barriers & Calorie Intake	.464	<.001
Perceived Barriers & Fiber Intake	-.316	<.001
Perceived Barriers & Calcium Intake	-.410	<.001
Perceived Barriers & Vit D Intake	-.452	<.001
Self-Efficacy & Calorie Intake	-.412	<.001
Self-Efficacy & Fiber Intake	.539	<.001
Self-Efficacy & Calcium Intake	-.240	<.001
Self-Efficacy & Vit D Intake	-.309	<.001

Aims 4 and 5 of the study, were to assess the relationship between perceived barriers and self-efficacy with calorie, fiber, calcium and vitamin D intake. Table 9 presents the correlation between barriers and self-efficacy with each of the nutrients, adjusted for age. The score of total constructs from the Nutrition and Health Awareness questionnaire ranged from 58 to 90. The score of dietary behavior from BAMBI questionnaire ranged from 33 to 90.

Table 10: Spearman correlations between parents' perceived susceptibility, severity and dietary behavior calorie intake of children with autism.

	<i>r_s</i>	<i>P-value</i>
Perceived Susceptibility & Dietary Behavior	.827	<.000
Perceived Severity and Dietary Behavior	-.667	<.000
Perceived Benefits & Dietary Behavior	.690	<.000
BMI Percentile & Dietary Behavior	-.384	<.000

Some of the secondary aims of this study were to access the relationship between parents' perceived susceptibility, severity, and benefits with their children's dietary behavior, as represented in table 10.

Table 11: Barriers & Self-efficacies in Parents

	Response %^a
Perceived Barriers	
• Affordability of fresh produce	50%
• Long hours of working	44%
• Transportation	47%
• Inability to cook	49%
Self-efficacy	
• No family support	48%
• Not part of any support groups	66%

^a- % of participants who rated the above dietary behaviors as 'Always'.

Table 11 presents commonly observed barriers and self-efficacy of parents of children with ASD who participated in the study and the percentage of responses as "Always" for each of the barriers and self-efficacy.

Table 12: Common Dietary Behavior Concerns

Dietary Behaviors	Response % ^a
<ul style="list-style-type: none"> Difficulty accepting new foods and resisting novel experiences that extends to tasting and trying new foods (<i>neophobia</i>). 	42%
<ul style="list-style-type: none"> Difficulty with transition to textures. 	80%
<ul style="list-style-type: none"> Restricted or selective intake based on food category, color, texture, consistency, appearance, taste, smell, brand, packaging, and food temperature. 	39%
<ul style="list-style-type: none"> Difficulty with mealtime presentations, e.g., specific plate and cutlery or positioning of food on a plate. 	47%
<ul style="list-style-type: none"> Increased sensory sensitivity (<i>tactile</i>) leading to rejecting foods because of aversion to temperature and texture. 	49%
<ul style="list-style-type: none"> Disruptive mealtime behaviors such as not staying seated at mealtimes or not eating with the family. 	71%
<ul style="list-style-type: none"> Persistently wanting the same foods or that food be made in a certain way. 	43%

^a- % of participants who rated the above dietary behaviors as 'Always'

Table 12 presents the most common feeding behavior concerns gathered from BAMBI and the percentage of responses as “always” for each of the behaviors.

Table 13: Coefficients of the logistic regression model for prediction of gastrointestinal symptoms in children with autism for all participants.

n=109	B (SE)	Odds Ratio	95% of Confidence Interval	
			Lower	Upper
Step 1				
Moisture	.000 (.000)	1.000	.999	1.000
Fiber	.011 (.007)	1.011	.997	1.026
GF/CF diet	-2.856 (.557)	.058	.019	.171
HEI Score	-.040 (.025)	.960	.915	1.008
Constant	7.956 (1.848)	2852.656		
Step 2 ^a				
GF/CF diet	-2.851 (.540)	.058	.020	.167
HEI Score	-.056 (.022)	.945	.906	.986
Constant	8.661 (1.775)	5773.936		

^a Nagelkerke R^2 = .560

One of the secondary aims was to assess the relationship between dietary intake and gastrointestinal symptoms. A logistic regression model was built for prediction of gastrointestinal

(GI) symptoms in the children, and among the four predictors included in the model (*fiber, moisture, GF/CF diet and HEI*), GF/CF diet and HEI Score were the significant predictors of GI symptoms, as seen in Table 13. The odds of having any GI symptoms were lower in children consuming GF/CF diets (*GF/CF*) and those participants who consumed components of HEI in adequate amounts.

Table 14: Median of Dietary Variables by Intake of Gluten-Free Casein Free (GF/CF) diet of children with autism living in the U.S.

Dietary Variables	Gluten-Free Casein-Free Diet ^a		P-value ^b
	Yes	No	
Calories (kcal)	1662	2614	0.000
Carbohydrates (g)	253.6	367.9	0.001
Protein (g)	67.8	76.8	0.135
Lipids (g)	80.2	106	0.005
Moisture (g)	985.4	1210.3	0.014
Fiber (g)	15.4	18.8	0.006

^a Special Diet-Gluten free/Casein free diet

^b P-values obtained from the Wilcoxon Rank-Sum test

Another secondary aim of this research study was to assess the relationship between dietary intake and GF/CF diets. Table 14 shows median daily intakes of macronutrients and calories for children living in the U.S., stratified by GF/CF diet consumption. The table indicates that those consuming GF/CF diets had significantly lower intakes of all dietary variables. In contrast, no significant differences were found in the children living in India (*data not shown*), which may be related to the fact that 70% of the children in India were on a GF/CF diet.

Discussion

The present cross-sectional descriptive study was conducted to assess attitudes and beliefs of parents towards their children diagnosed with ASD and how these attitudes and beliefs may be associated with dietary intake and diet-related behaviors.

Participants recruited for this study were from diverse geographic locations and ethnicities. About 60% of the study participants were in the elementary school age. It was an interesting observation to see that the average age among the Indian participants was 11 years (*middle school age*). It is unknown if the Pediatric Association in India recommends screening for ASD at a specific age. However, the American Academy of Pediatrics advises that all children be screened for autism at 18 months and at 24 months. The average age at which children have a diagnosis for autism is 4 years in the U.S.¹⁷³

The ratio of boys to girls in the study population was 7:1. These findings are not in line with those of a recent study conducted by Loomes et al,¹⁷² which reported a male-to-female ratio of 3:1. One likely explanation for the contrasting results could be the smaller sample size of the present study. In the study by Loomes et al,¹⁷² the objective was to originate the first systematically calculated value of the proportion of boys and girls with ASD through a meta-analysis of prevalence studies conducted since the introduction of the DSM-5 and the International Classification of Diseases, Tenth Revision. The authors concluded that the true male-to-female ratio is not 4:1, as is often concluded; rather, it is closer to 3:1.

Parents of children with autism often complain a high rate of gastrointestinal symptoms,¹⁷⁴ in spite of the lack of medical causes. Present study also had similar results. Around 60% of the children in the study had GI symptoms, the most common of which was constipation. Amongst the children with GI issues 80% were from the US and only 20% from India which was an interesting observation from the data analysis. These findings seemed to relate to the use of GF/CF diets as children with GI symptoms were also reported to not follow GF/CF diets. The underlying cause of gastrointestinal symptoms in patients with ASD is not exactly known, the most widely accepted theory is the opioid theory,¹⁷⁵ which proposes that incompletely digested peptides act as

opioid agonists reducing pain sensitivity and increasing the severity of autism-specific behaviors. That is opioid peptides which is a result through metabolism of gluten and casein enter through a permeable intestinal membrane and then proceed to exert an impact on neurotransmission through combining with opioid receptors.¹⁷⁵ Thus, a notion that the GF/CF diet may have a beneficial effect to support the opioid theory by researchers and parents. Since the studies are generally applied to a small number of subjects for short periods, the effect of this diet on autistic behavior is not clear. Elimination diet (*GF/CF*) increases the time and cost of food shopping and preparation. Studies report that gluten-free (*GF*) products are more expensive (*by 240%*) compared to the same type of product that contains gluten and that gluten-free products are limited.¹⁷⁶ Therefore, the high cost of elimination diets could be considered as one of the challenges.

The mean HEI score of the study participants with autism was 70. The average HEI score from a 2015-2016 NHANES dataset for children aged 6-17 was reported to be 53,¹⁶⁹ which was not expected and does not support our hypothesis that the HEI score of children with autism would be lower than the scores of their typically developing counterparts. Since the dietary intake in Indian participants were very distinct from US participants due to cultural and food availability differences, the HEI scores for both the groups were calculated separately. The mean Healthy Eating Index (*HEI*) score among the Indian children (83) was considerably higher than that of U.S. children (65). One explanation for the higher HEI scores in the children living in India was the adequacy of certain HEI components (*whole grains, vegetables, whole fruits, and legumes*). Excess consumption of refined grains, added sugars, and fatty foods explains the lower HEI scores of the U.S. children and, possibly, the high incidence of GI symptoms in this group. On the other hand, the fact that the HEI score of U.S. children with ASD was higher than that of a nationally representative sample of children 6-17 years may indicate that parents of ASD children are making

an extra effort to include healthier foods in their children's diets. One noticeable general difference between the diets of children from the U.S. and India was the presence of wholly fermented foods, pickle and baked fryums* in the diet of Indian children. The inclusion of fermented foods may increase intake of probiotics,¹⁷⁷ which may contribute to lower incidence of GI symptoms in these children. In contrast, fermented foods, pickles and fryums have a high content of sodium, which contributed significantly to the high intake of sodium observed in the Indian participants (*HEI radar plot*). Among the U.S. children, despite the high consumption of processed foods and fast foods, the sodium was considerably lower. A review by Ledford et al¹⁷⁸ synthesized research papers regarding the types of feeding problem in children with autism in the elementary age group. The authors had not found significant differences in the intake of total calories, carbohydrates, or fat between children with ASD and typically developed children, suggesting that the mechanism of feeling full are not impaired. Although children with Autism eat less variety of foods, iron, zinc, magnesium, and phosphorus intakes in children were adequate, in this study. Calcium and vitamin D intakes were inadequate in this study. Schmitt et al⁵⁰ compared the intake of nutrients from food consumed by children (2-11) in the U.S. with and without ASD and examined the deficiency and excess in the nutrient intakes. Children with ASD, were similar to other children in America, consumed less than the recommended amounts of calcium, vitamin D, vitamin A and vitamin B12 from food. In another study,¹⁷⁹ Bandini et al assessed the impact of food selectivity on nutrient adequacy among 3-11 years children in the U.S. Findings of their study suggested that limited food repertoire may be associated with nutrient inadequacies, especially micronutrients like calcium, zinc, iron and vitamins. Nutrient deficiencies combined with difficulties in feeding displayed by

* Indian snack food composed primarily of potato starch, tapioca and tinted sago – used as side dish to a meal.

this population elucidated the need of supplementation with these essential nutrients as well as antioxidants.

Eighty nine percent of the children with autism exhibit nutritional challenges⁵⁵ in general. For example, extreme food selectivity, ritualistic eating behaviors and nutrition inadequacies. This is particularly of concern because autism now presents as a public health problem. To the best of our knowledge, there is no study that has investigated the possible barriers and self-efficacy from the parent's perspective that could affect the child's dietary behavior and well-being. The results of this study indicate that the higher the barriers, the lower the dietary behavior score. For most parents, the common barriers were the affordability of fresh produce, long hours of working, transportation, and inability to cook. Parent self-efficacy was positively related to BAMBI score. The parents whose self-efficacy scores were high, had a good family support and were in a support group updating themselves with various techniques to improve their children's nutritional status. It was also found that the higher the barriers, the greater the calorie intake of the children, with a lack of healthier options (*whole foods, fruits, and vegetables*). In contrast, the higher the parents' self-efficacy scores, the lower was the calorie intake of the children, which was accompanied by intake of healthier food options. This finding illustrates how some of the barriers and self-efficacy with respect to parents and caregivers could affect the dietary behavior and dietary intake of children with autism. More investigation needs to be done in this area, to identify other possible barriers that could impact children's dietary behavior and intake. The partial correlation coefficient indicated that there was no difference between the HBM constructs and dietary behavior, with and without factoring age of the participants.

The present study has similar results to a study by Rodenburg et al,¹⁰⁷ for perceived knowledge, perceived severity, and perceived benefits with respect to the dietary behavior in

children. Rodenburg et al¹⁰⁷ examined the association between parental and child food consumption in the context of general parenting, education level in parents and the ethnicity of the families. Parental education and child healthy food consumption were positively associated; the higher knowledge and perceived benefits of parents, was correlated with healthier dietary behavior in their children with autism. The range of BMI percentile is wide, where the median (97.9%) is in the obese category and more than 50% of the population fall in this category. The BMI percentile amongst the girls in the population is better than the boys. CDC indicates that an estimated 19.3% of U.S. children and adolescents aged 2–19 years are obese.¹⁸⁰ This study has similar results to the study conducted by Hill et al,¹⁸¹ where the obesity prevalence in children with autism is higher than typically growing children of the same age range. In the study by Hill et al,¹⁸¹ there were 5053 participants with confirmed diagnosis of ASD in the Autism Speaks Autism Treatment Network. Measured numbers for height and weight were used to calculate the BMI percentiles; Overweight and obesity was defined using the CDC criteria for BMI for age and gender (*≥85th and ≥95th percentiles, respectively*). The results concluded that the prevalence of unhealthy weight is significantly greater among children with ASD as compared with the general population. The consensus report by Buie et al¹⁸² also signify that children with autism also have the possibility to be obese in addition to nutritional inadequacy.

The feeding assessment surveys filled in by the parents/caregivers denoted that the major feeding problem among children was food selectivity, transition to textures, staying on seat at mealtimes, and meal presentation. The afore mentioned feeding behavior concerns reported in this study as illustrated in table 12 and 13 were similar to the study conducted by Chistol et al.¹⁸³ The study conducted by Chistol et al¹⁸³ compared the processing of oral sensation between children with and without ASD, ages 3–11 years. They also studied the relationships between atypical oral sensation

process, selection of foods, and consumption of fruits/vegetables in children with ASD. The study found that children with ASD presenting with atypical oral sensations were higher than children without ASD. Among children with ASD, those with atypical oral sensations refused more foods and vegetable consumption was very less than those with typical oral sensations.

This study as part of its secondary aim looked at the relationship between intake of some nutrients and GI symptoms. We found that a GF/CF diet was an important predictor of GI symptoms in both groups of children from the U.S. and India. Our findings indicate that children who were on the GF/CF diet had less GI symptoms (*constipation*). An interesting finding from this study, was that the GF/CF diet was more a predominant predictor than moisture and fiber as a contributing factor to ease out GI symptoms, especially constipation which was the most common GI symptoms seen in children in this study. Considering that a GF/CF diet (*GF/CF*) is becoming more common among the parents of children with autism, the study compared macronutrient intake of children consuming a GF/CF diet versus children consuming a regular diet. The intake of all macronutrients was lower in children consuming a GF/CF diet compared with children on a regular diet. Reports from parents who participated in the present study indicated that some children were not able to adhere to a GF/CF diet, and food intake was increased when these children were offered a regular diet. More studies are needed to investigate the effectiveness of a GF/CF diet to prevent GI symptoms and provide adequate nutrient intake for children with autism. It should be noted that a GF/CF diet may not provide adequate calcium if not carefully planned. Our findings suggest that intake of a GF/CF diet may be associated with low calcium, as consumption of dairy products does not occur. It was interesting to note that in the Indian participants, more than 80% of the children were on a GF/CF diet, which is a relatively normal practice. Consumption of refined foods was very minimal as gathered from the interview with the

parents and as shown from the HEI radar plot. Millet was their staple carbohydrate which is a good source of calcium and contributed to calcium adequacy in the Indian children. Constipation was not a major concern in the Indian participants as most of them were on GF/CF and had high fiber intake.

Strengths and Limitations

Strengths of these study are the use of HEI scores to assess the diets of children with autism in the age range of 5 to 13 years, and the fact that data were collected from two distinct groups of children, living in different parts of the world. Some limitations of this study include the cross-sectional nature of the design, which does not permit us to study causal relationships between variables, the fact that the answers to the Nutrition & Health Awareness questionnaire and BAMBI were self-reported and the fact that some sections of the Nutrition & Health Awareness questionnaire were not applicable to the children in India. For example: “I do not have transportation to get to places”, most people in India use public transport; “I get food assistance”, the concept of government food aids does not exist in India. Hence, all the surveys of the Indian participants were completed over phone by the investigator for better interpretation, and the data were also analyzed separately due to inherent differences in dietary patterns in the two groups that could not be separated from the cultural differences. The 24hr recall was based on what the participants’ parents remembered at the time of the telephonic interview with the investigator. There is always a chance that some foods were not recollected or that parents’ may not have been fully aware of all foods their children consumed during a 24-hr period. Some children were also taking supplements for which we could not get nutritional values. Due to privacy laws, the severity of the participants’ condition could not be assessed, which would have provided additional insight into the relationship between dietary behavior and autism severity.

Conclusions

In conclusion, high perceived barriers and low self-efficacy of parents were associated with more dietary behavior problems, GI symptoms, i.e., constipation, sleep issues and high BMI in children with autism. Children with autism living in the U.S. had higher diet quality as assessed by the Healthy Eating Index as compared to their counterparts. Interventions targeting parent and caregiver attitudes and beliefs are necessary for promoting healthy dietary habits in children with autism.

Implications of the study

There is no one magic rule to fit the needs of the parents with barriers and self-efficacy issues but the possible solutions are illustrated out in figure 13. As only 5% of the total population of this study has seen a nutritionist for consultation and as we have seen diet does play a substantial role in well-being of children with autism, it is important and should be made mandatory for all parents to get a nutritional counselling. This should be covered by the insurance so that parents get encouraged to consult with one. After extensive investigation of insurance for nutrition care services, for children with ASD, there was no evidence to substantiate the fact that Nutrition Services are covered by Affordable Care Act (*ACA*) or Medicare or Medicaid. However, some private high premium insurers (*BCBS, Aetna, CIGNA*) provide nutrition services under preventive care. This asserts the data collected in this study that only 5% of the participants have consulted a Registered Dietitian for nutrition counselling, probably due to their financial situation. Interaction with parents made it very evident that parents want immediate help, outside office hours. This concern could be addressed by making short scenario videos for parents to access easily through their phone or also have a HOTLINE available, where nutritionists are able to assess the problem at the time of the call and suggest a quick, viable and healthy remedy for parents to implement, provided that the first assessment has been made in person by the nutritionist (*RD*). Another

possible implication related to nutritional assistance, could be to provide an ASD Dietary Alarm Guide, which could be used by non-healthcare professionals (*caregivers, teachers and parents*) to identify early signs of ASD, as research has proven that early intervention could have better management of dietary behaviors in children with autism.

Many of the parents were not part of any support group and some of them were not even aware of what the groups meant. It is important for the health care providers to share this information with the parents especially for those who are single parent and do not have any support system. Another most important information the health care providers could provide is the food assistance package and direct the parents to correct authorities to seek help to buy healthy foods and make it available for their children. Some of the parents could not afford the therapies for their children which is very essential to help the kids with autism to combat with daily activities and help them lead a life close to their counterparts of their age. These therapies may also be covered by government aid or train the parents to do these sessions at home with their children. Parents manipulate children's eating behavior in a variety of ways: parents make food choices for the family, serve as example for dietary choices and patterns, and use feeding styles to reinforce the development of eating patterns and behaviors that they think is appropriate. Parenting practices are also dependent by the child's characteristics, including age, gender, weight status and eating behavior. Thus, parent and child inter affect and respond to one another's eating behavior. When children observed the eating behavior of their peers and family, the effect was identical such that there was an increase in selection and consumption of vegetables.¹⁸⁴ Thus, positive social modeling is a roundabout, yet the best practice for promoting healthier diets in children. In conjunction with what is known about the effect of parental modeling on children's eating behaviors there is constant proof that the responsive “do as I do” behavior has a strong positive

effect on children's consumption patterns than the unresponsive “do as I say” behavior of parenting.

To address parent support constraints, peer-counselling could be a viable solution, whereby health-care professionals could inform peer-counselors through National Organizations (*like Autism Speaks*) to reach out to families for support and assistance. Parents who are unable to provide healthy hot meals, due to their barriers seen in this study, could avail hot dinners, provided by the government at a subsidized rate, via Meals on Wheels program.

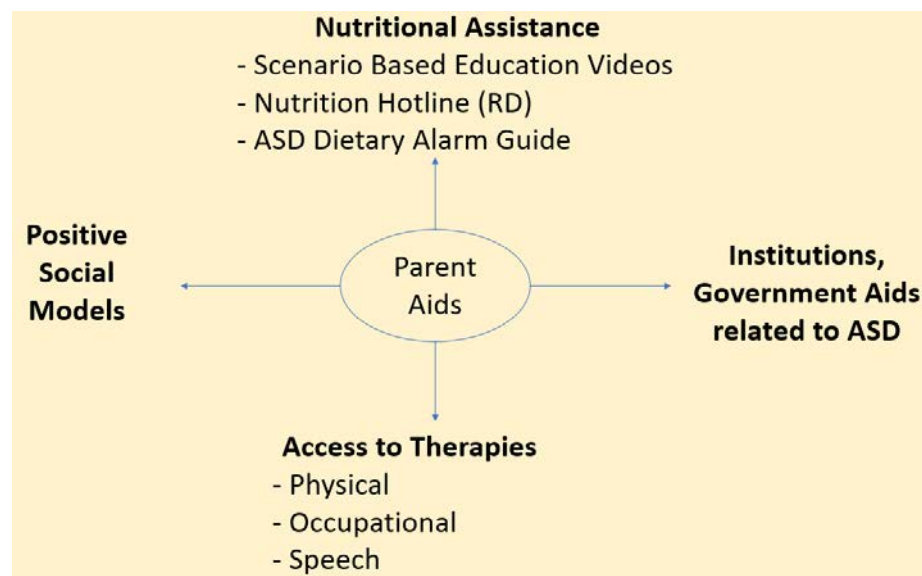


Figure 13: Parent Tools to aid with improving dietary behavior in children, with respect to Parent's Barriers and Self-efficacy.

Experiences with diet and food selection begin in infancy and continue to develop as children grow into adults and transition to solid foods is a well-established fact. During this growing up time, children's food choices are also based off availability, accessibility, and familiarity to foods as well as parenting and modeling. Thus, if children are to learn to like and select healthy nutritious foods, they need start early, positive, repeated experiences with those foods. Thus, aspects of parent and caregiver behavior related to feeding practices with children should be approached by education, prevention, and intervention efforts. Reinforcement should be

in family, school and community environments as these surroundings continually have effects on and interplay with characteristics and behaviors of both children with autism and their parents.

Additional Interesting Observations

Some interesting facts were gathered at the time of diet recall, with the mothers of Indian children with autism. In most households, children live with their grandparents, uncles, and aunts as joint family. Many mothers are home makers and always available for their children with special needs. Due to the joint nature of living, there is always a good support system to nurture the growing child in all aspects. Food consumed by the child is home prepared from fresh produce. Use of probiotics in the form of fermented foods and home-made yogurt is a common practice and fermented foods are part of their daily diet. Goat's milk is consumed instead of cow's milk, because it is perceived as healthier.¹⁸⁵ and the mothers believe that it is easier to digest. A variety of spices like ginger, garlic and turmeric are used in the daily cooking. These spices are known for their health benefits (*antioxidants, anti-inflammatory, and calming stomach*). Coconut water and Kanji (*gruel/rice water*) were the drinks used as beverages instead of soda and juices. Many parents saw an opportunity to spend more quality time with their children during the covid pandemic. Some reported trying to introduce new fruits and vegetables into their children's diets as well as experimenting with new recipes to expand the variety in their children's diets. Vitamins and minerals were administered in the form of Ayurvedic herbs, for which the nutritional information was unavailable. There were also reports of children undergoing a biomedical intervention, which seemed to include a de-yeasting procedure once a year for which, details were also not available.

In contrast to the dietary patterns of the Indian children, U.S. children consumed more processed and fast foods. Figure 14 illustrates the characteristics of the diet patterns of the two groups of children.

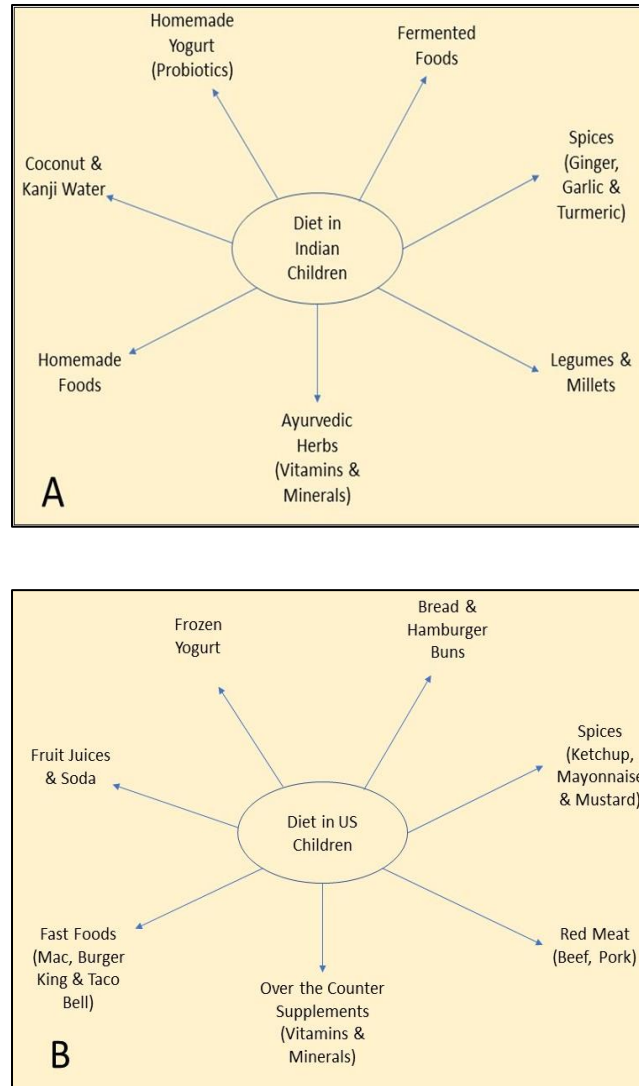


Figure 14: Dietary Patterns in children from India (Panel A) & US (Panel B), indicating the differences of food intake.

Figure 14 suggests that nutritional professionals could consider use of certain dietary habits, as seen from dietary intakes of Indian children, to promote healthy eating behaviors, in children with autism in the US.

Appendix A

Protocol Title: <i>Parents attitudes and beliefs towards dietary behaviors of children aged 5-13 years with special needs</i>
Principal Investigator: Ms. Subashree Narayanan, MSH.
Description of Subject Population: Children in the age range of 5-13 years with special needs
Version Date: July 2020

Parental Consent Form for Research

The purpose of this form is to provide you with information about taking part in a research study. Please read this form carefully. Your child is invited to take part in a research study "Parents attitudes and beliefs towards dietary behaviors of children aged 5-13 years with special needs" If you have any questions about the research or any portion of this form, please ask us. If you decide to take part in this research study with your child, we will ask you to sign this form. You (Parent/Guardian) must be at least 18 years of age. You will be provided with a copy of the signed form.

The researcher in charge of this study is Ms. Subashree Narayanan, MSH; from University of North Florida (UNF), and she is doing this as part of her dissertation project for the Doctoral program she is in. She can be reached at Redacted or via email at Redacted

Why is this study being done?

Previous studies have reported that children diagnosed with autism spectrum disorders and other neurological and developmental disorders lack some good bacteria in their gut, and also have issues with their GI function, sleep and many other discomforts. These studies have concluded that these children lack in some important nutrients like protein, calcium and some vitamins. There has not been any study which analyzes dietary pattern and co relate it with the comorbidities seen in children with special needs. The purpose of this study is to evaluate the dietary patterns of the study participant and establish any correlation between lack of nutrients in their diet and the comorbidities. As part of this study, parents/guardians would be asked to fill out few onetime questionnaires and a 24hr dietary recall for a week. Children will not be directly involved in the study.

Why am I and my child being asked to participate?

We are asking for your child to take part in this study because she/he is between the ages of 5 and 13 years, diagnosed with Autism Spectrum Disorder and is a picky eater with meal-time behavior issues. The research is self-funded by the researcher.

How long will my child and I take part in this research study?

Your child will not be directly involved in the study; however, you would have to fill out a couple of one-time questionnaires and a 24-hour dietary recall for a week.

What will I have to do if I decide to participate in this research study?

If you agree to take part in this study, we will ask you to read through and sign the consent form before we proceed with the study.

As you choose the mode of communication (email, WhatsApp, Facebook, etc) we would forward the questionnaires.

Study Title: Parents attitudes and beliefs towards dietary behaviors of children aged 5-13 years with special needs
IRB Protocol Number: _____
Consent Form Validity: _____
Study Expiration Date: _____

Children with Special Needs 5 – 13 years – "Parental Consent Form"

1

The questionnaires you will be asked to fill out are:

- General Questionnaire (2 minutes)
- Nutrition & Health Awareness Questionnaire (5 minutes)
- Eating Habits – BAMBI (5 mins)
- ASA 24 hr Diet Recall (Over the phone with Principle Investigator, at an agreeable time) (5 minutes)

Once you fill out the questionnaires, you could scan or mail the same to the Principal Investigator at the following mailing address: Subashree Narayanan, 6940 Azalea Grove Dr, Jacksonville, FL 32258.

If you do not choose one of the listed forms of communication, above, then the Principal Investigator could fill out the forms with you over the phone at your convenience.

Will My Information Be Kept Confidential?

The records of this study will be kept confidential, as all study documents will be identified by a unique study ID. The unique study ID will be linked to your name and your child's name in only one file which will be stored in a password protected computer. Access to this file will be limited to the principal investigator. We will make every effort to keep your records confidential. However, there are times when federal or state law requires the disclosure of your records. Your child's study records will be stored for 7 years following the end of the study.

As part of this study, you will be asked to provide information from your child's medical record, such as any allergies, medication and any other condition that the investigator should be aware of. This information will not be shared with anyone else other than the principal investigator.

The results of this research study may be published or used for teaching. We will not put identifiable information on data that are used for this study. All forms that will be filled, will be substituted and referenced by an unique study ID for research confidentiality.

Study Participation and Early Withdrawal

It is your choice whether you and your child take part in this study. You are free to withdraw at any time for any reason. No matter what you decide, there will be no penalty or loss of benefit to which you are entitled.

What are the risks of participating in this research study?

There are no foreseeable physical or psychological risks to participants in this study, as the participant is not directly involved with the study.

Benefits

Although you may not benefit directly from this study, information gained in this process may allow researchers and practitioners to know what services are most commonly being provided to children with ASD. This may lead to better training for school psychologists and other professionals.

Are there any benefits for participating in this research study?

Although there are no direct benefits to or compensation for taking part in this study, you and others may benefit from the information we learn from the results of this study.

Study Title: Parents attitudes and beliefs towards dietary behaviors of children aged 5-13 years with special needs
IRB Protocol Number: _____
Consent Form Validity: _____
Study Expiration Date: _____

By the 24-hour dietary recall for a week, it will give a good understanding for what is consumed, which otherwise one would not pay so much attention to. This will help act as a positive incentive to continue to eat healthy, otherwise will help identify the meal that could be altered and made healthier. It will also help to identify other areas (Non-dietary) to combat the co-morbidities for the child to lead a healthy normal life.

Ultimately, we expect that this study will contribute to the advances in clinical practice related to treatment for children with special needs.

Will it cost me to take part in this research study?

There are no costs to you for taking part in this research study.

If I have any questions or concerns about this research study, whom can I talk to?

You can call the principal investigator, Ms. Subashree Narayanan, MSH with any concerns or questions at **Redacted** or email at **Redacted**

If you have questions about your rights as a research subject or want to speak with someone independent of the research team, you may contact the University of North Florida IRB directly by phone at (904) 620-2498 or email at irb@unf.edu.

PARENT'S CONSENT:

I have read the information in this consent form, including risks and possible benefits. I have been given the chance to ask questions. My questions have been answered to my satisfaction, and I agree to participating in the study. I have been given a copy of this form.

(please select one option below)

- ☐ By checking this box, I **DO** give consent to participate in this study
- ☐ By checking this box, I do **NOT** give consent to participate in this study

Name of Child

Name of Parent/Guardian

Signature of Parent/Guardian

Date

----- **Administrative Section** -----

I have explained the research to the subject and answered all his/her questions. I will give a copy of the signed consent form to the subject.

Name of Person Obtaining Consent

Signature of Person Obtaining Consent

Date

Study Title: Parents attitudes and beliefs towards dietary behaviors of children aged 5-13 years with special needs
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IRB Protocol Number: _____

Consent Form Validity: _____

Study Expiration Date: _____

Children with Special Needs 5 – 13 years – “Parental Consent Form”

3

Appendix B

General Questionnaire

Child details

First Name: _____ Last Name: _____

Zip Code: _____ Race: _____

Gender: M F (please circle) Age: _____ Height: _____(in) Weight: _____(lb)

Parent/Caregiver Details

First Name: _____ Last Name: _____

Zip Code: _____ Gender: _____

Relationship to Child: _____ Marital Status: _____

Are you the Primary Caregiver of the child? Yes / No (please circle)

Are you currently?

_____ Employed for Wages _____ A homemaker

_____ Self-Employed _____ A student

_____ Out of work for more than 1 yr. _____ Retired

_____ Out of work for less than 1 yr. _____ Unable to work

What is your highest qualification?

_____ Less than High School Diploma _____ 1-3 yrs. of College

_____ High School or GED _____ 4 yrs. and more

Pertinent Information

❖ Does your child have any Sleep Issues? Yes / No (please circle)

If yes, provide details: _____

❖ Does your child participate in any special programs? Yes / No (please circle)

If yes, provide details: _____

❖ Does the child exhibit any GI discomfort?

• **Constipation**

☐ Reduced Defecation Frequency

☐ Low Amount of Feces

☐ Dry Stool

☐ Great Effort to Defecate

• **Chronic Diarrhea**

☐ High Frequency of Defecation

☐ Loose Stools (for more than 2 months)

• **Flatulence**

☐ Hiccup

☐ Passing Gas

☐ Disgorging (Burping)

Appendix C

Nutrition & Health Awareness Questionnaire

SECTION I	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1 My child will probably develop serious health conditions as an adult	1	2	3	4	5
2 My child probably cannot live an individual life with his health condition	1	2	3	4	5
3 There is very less chance for my child to develop any complications as an adult	1	2	3	4	5
4 My child will not develop any health complications as an adult	1	2	3	4	5
5 I am worried about my child's future health conditions	1	2	3	4	5
6 I am confident about my nutrition knowledge	1	2	3	4	5
7 I would like to obtain more nutrition information	1	2	3	4	5
8 I have seen a registered dietitian for my child	1	2	3	4	5

SECTION II	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
9 I believe my child is well nourished	1	2	3	4	5
10 I do not believe my child is getting adequate amounts of vitamins/minerals	1	2	3	4	5
11 I believe my child is getting enough to eat	1	2	3	4	5
12 I believe my child is underweight	1	2	3	4	5
13 I believe my child is overweight	1	2	3	4	5

SECTION III	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
14 I cannot afford to get fresh produce	1	2	3	4	5
15 I do not have transportation to get to places	1	2	3	4	5
16 I do not know how to cook	1	2	3	4	5
17 I cook on weekends	1	2	3	4	5
18 I work long hours, and so cannot cook on weekdays	1	2	3	4	5
19 my child cannot do any physical activities due to his condition	1	2	3	4	5

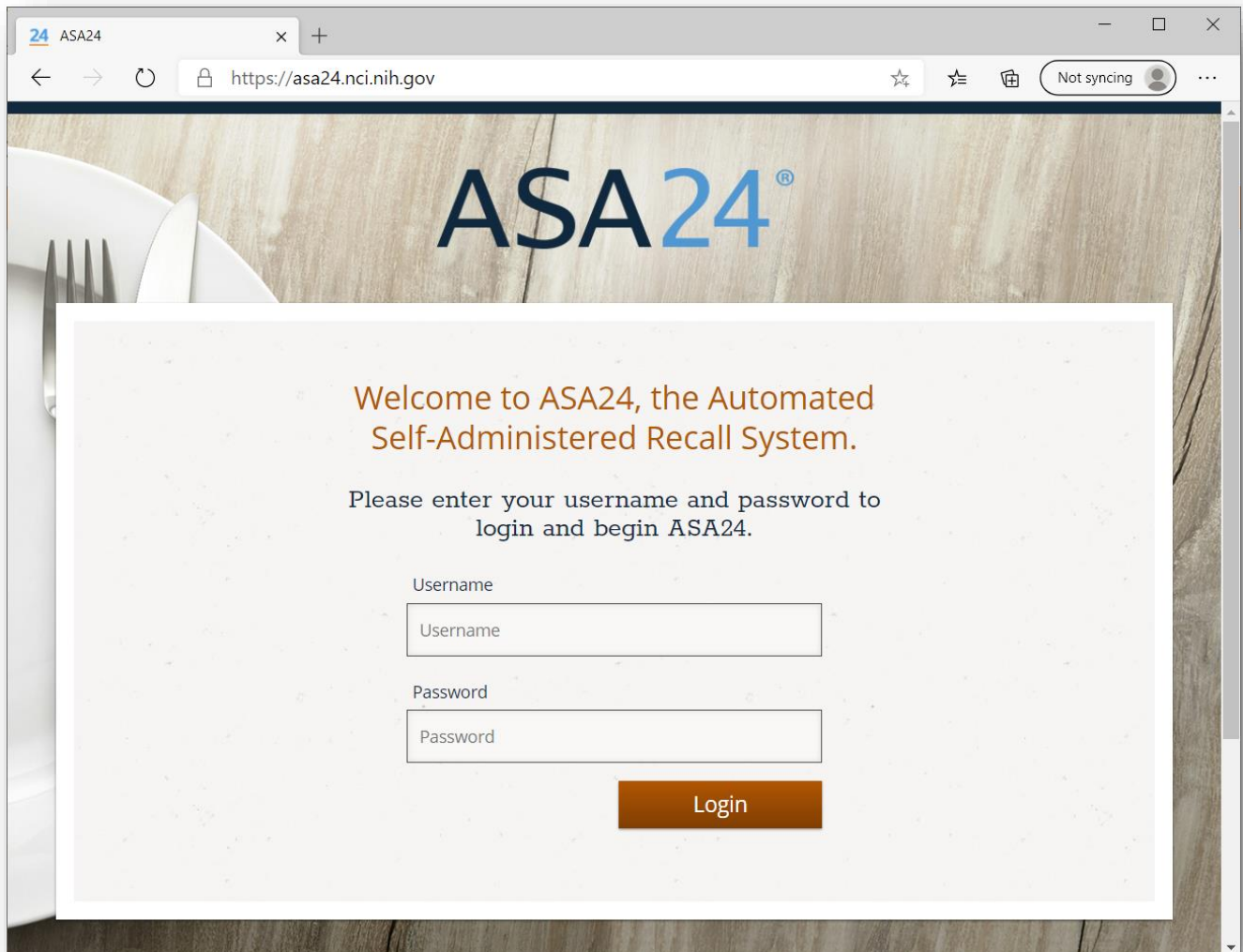
SECTION IV	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
20 I get food assistance	1	2	3	4	5
21 I will get fresh produce with food assistance	1	2	3	4	5
22 I do not know about any special diets	1	2	3	4	5
23 I would like to try special diets (Gluten/Casein-free) for my child	1	2	3	4	5
24 I would obtain nutrition information from family and friends	1	2	3	4	5
25 I do not feel I am well informed about nutrition for my child	1	2	3	4	5
26 I am part of a support group for nutrition related information	1	2	3	4	5
27 I will not be part of any nutrition support group for my child	1	2	3	4	5

Appendix D

Eating Habits (BAMBI)						
Child Perspective						
		Always	Often	Occasionally	Seldom	Never
1	Cries or screams at mealtimes	5	4	3	2	1
2	Turns his/her face or body away from food	5	4	3	2	1
3	Remains seated at the table until meal is finished	5	4	3	2	1
4	Expels food that he/she has eaten	5	4	3	2	1
5	Aggressive during mealtimes	5	4	3	2	1
6	Displays self-injurious behavior during mealtimes	5	4	3	2	1
7	Is disruptive during mealtimes	5	4	3	2	1
8	Closes mouth tightly when food is presented	5	4	3	2	1
9	Is flexible about mealtime routines	5	4	3	2	1
10	Is willing to try new foods	5	4	3	2	1
11	Dislikes certain foods and will not eat them	5	4	3	2	1
12	Refuses to eat foods that require a lot of chewing	5	4	3	2	1
13	Prefers same food at each meal	5	4	3	2	1
14	Prefers crunchy foods	5	4	3	2	1
15	Accepts or prefers a variety of foods	5	4	3	2	1
16	Prefers to have food served in a particular way	5	4	3	2	1
17	Prefers only sweet foods	5	4	3	2	1
18	Prefers food prepared in a certain way (fried and greasy)	5	4	3	2	1

3
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Appendix E



The screenshot shows a web browser window with the URL <https://asa24.nci.nih.gov>. The page features a background image of a wooden table with a white plate and silverware. The ASA24 logo is prominently displayed at the top. A white login box is centered on the page, containing a welcome message, instructions, and input fields for username and password, along with a login button.

ASA24[®]

Welcome to ASA24, the Automated Self-Administered Recall System.

Please enter your username and password to login and begin ASA24.

Username

Password

Login

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