INTRODUCTION, DESCRIPTION, AND INCIDENCE

Autism Spectrum Disorders (ASD) include three of the five Pervasive Developmental Disorders (PDD). PDDs are a category of neurological disorders which include qualitative impairment in several areas of development including socialization and communication as well as behaviors, interests and/or activities which can have a restricted, repetitive, and/or stereotyped pattern. Individuals diagnosed with ASD are affected in different ways that can range from mild to severe. Currently, the Diagnostic and Statistical Manual—Fourth Edition—Text Revision (DSM-IV-TR) includes 12 criteria used in making an ASD diagnosis, not all of which need to be present in order to make this diagnosis. Different ASD diagnoses require a different number and/or type of criteria. In DSM-IV-TR, additional factors such as early history of language delay and intellectual functioning also play a role in determining which ASD diagnosis is assigned. Consequently, children who share the same diagnostic label of autism may vary widely in the appearance of symptoms, the severity, and how the symptoms are expressed. No single biological cause for ASD has been identified, and it is believed that there are numerous etiologies, including a strong genetic component. Other identified differences include immunology, structural and functional brain differences, and neurological abnormalities.

Autistic Disorder (also called “classic” autism)

This is what most people think of when hearing the word “autism.” Individuals with autistic disorder had, or still may have, significant language delays, social and communication challenges, and unusual behaviors and interests. Many with autistic disorders also have intellectual disability. However, there are also those who have met sufficient criteria for a diagnosis of Autistic Disorder yet don’t have intellectual disability; this is generally referred to as “High Functioning Autism,” though there is not yet a universally accepted definition. In fact, it is possible to have Autistic Disorder and be intellectually gifted.

Asperger Syndrome

Individuals with Asperger syndrome may or may not have some milder symptoms of autism. They might have social challenges and unusual behaviors and interests. However, they typically do not have problems with language delays or intellectual disability, though social communication skills are usually impacted.

Figure 1 – Pervasive Developmental Disorders

Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS; also called “atypical autism”)

Those individuals who do not meet enough of the DSM-IV-TR criteria for either Autistic Disorder or Asperger Disorder may be diagnosed with PDD-NOS.

It is a common misconception that those with PDD-NOS or Asperger Syndrome have milder symptoms than individuals with Autistic Disorder. While this is true in many cases, there are various reasons why PDD-NOS (or similarly Asperger Syndrome) may not actually indicate an individual has “mild Autism.” For example, an individual may not exhibit a sufficient number of ASD criteria for an Autistic Disorder or Asperger Syndrome diagnosis, yet this individual has one characteristic (e.g., fascination with unusual object or topic) that in fact interferes significantly with that person’s functioning in the world. Another scenario is that in which the “Autistic Disorder” diagnosis is not initially made due to lack of specialized expertise in ASD by the health care professional or the belief that PDD-NOS diagnosis would be more easily received by the parents.

Which ASD diagnosis gets assigned to an individual can have important ramifications for access to services, particularly those provided by the state or by public schools. Yet, recommendations for interventions do not differ based upon which ASD diagnosis an individual has because of the tremendous range of strengths and challenges in any single child. Due to the limitations of assigning one ASD diagnosis over another, there is currently a move to remove the separate ASD diagnoses and instead use the ASD diagnosis along with various qualitative descriptors about language level, etc. The specifics of this plan are not yet set, but are being addressed in the updating of the DSM-5 which is expected to be published in 2012.

Autism (the classic form of ASD) affects 1 child per 110, with 4-5 times more boys than girls diagnosed with the disorder. A recent survey of parents found a reported prevalence of 1 in 91 children. Reports indicate an incidence of autism in 0.6% to 1% of the general population. For a family with one child with autism, the recurrence risk is 2-8% to have another child with the disorder. In identical twins, if one child has autism, there is a 60-96% chance of the other twin being diagnosed. Family studies have shown increased rates of autism in first-degree relatives, as well as more frequent social difficulties, communication and learning deficits, stereotypical behaviors and anxiety disorder among family members. A number of genes and specific mutations have been linked to autism, and research in this area is expanding; it is believed that genetic research will yield a multi-gene cause of the disorders.

Early diagnosis is optimal (i.e., between the ages of 16 months and three years of age) to maximize services. Many children with autism develop typically during infancy, and symptoms present when the child is a toddler or preschooler. Often, speech and communication regress. Clinical deficits that may be present in some individuals with autism are described by Rapin and Tuchman and include impairments in or problems with cognition, executive function, attention, mood/affect, expressive language, language comprehension, play, taste/olfaction, and motor skills. Intellectual Disability (intelligence quotient <=70) is also present in 30-51% (41% on average) of children with ASD. Children with Asperger syndrome have normal IQs. Between 11 and 39 percent of children with ASD have seizures. The risk of seizures is higher in individuals with more severe intellectual disability (mental retardation).

DIAGNOSIS

Since there are no biological markers for autism, diagnosis is made by behavioral assessment through observations of the child’s behavior. The American Academy of Pediatrics, the American Academy of Neurology, and the Child Neurology Society all recommend developmental screening for young children at all well-child check-ups with an autism-specific screen at 18 months and an additional screen at 24-30 months to observe regression. For children younger than 3 years of age, red flags include problems with eye contact, joint attention (ability to share attention with another person), nonverbal communication, pretend play, paying attention to one’s name, and language development, as well as regression in these skills. A recent prospective study found that children diagnosed with autism were slow to progress to solid foods as infants and had a less varied diet after 15 months of age but energy intake and growth were not impaired.

If screening is positive, a comprehensive evaluation is indicated, including medical, cognitive, and communication assessments. Individuals with ASD can have one or more other developmental disabilities referred to as dual diagnosis, comorbidity, or co-existing conditions. For example a child with Down syndrome can also be diagnosed with autism; a child with autism can also be diagnosed with anxiety disorder and/or Tourette syndrome and/or a learning disability. Table 1 shows some common behavioral features of children with ASD. Not all behaviors are seen in all children.

With the diagnosis of ASD, referral should be made for early intervention services, special education, and related therapies. Treatment includes a variety of behavioral, developmental, and educational approaches, including applied behavior analysis, communication-focused interventions (e.g., sign language training), social skills development intervention (e.g., Social StoriesTM), and integrative programs. Many children need a variety of combined approaches to meet their individual needs. Early intensive intervention results in improvement for many preschoolers.
with services through early intervention programs (i.e., birth-to-three centers or programs) and specialized preschool education. Services continue within the school setting. Many families also receive therapy through private therapists and educators. Although children are getting identified at younger and younger ages, there remain individuals who do not receive a diagnosis until school age or later. See RESOURCES 1-5 for more information.

### NUTRITION AND FEEDING CONCERNS

#### Introduction

Parents of children with ASD often report that their children are picky eaters or have selective eating behaviors. Families are concerned about the nutritional adequacy of their children's intake and growth. Parents also report that their children with ASD may have gastrointestinal problems including constipation, diarrhea, and abdominal discomfort and/or irritability. Medications used in some children with autism may affect their nutrition status. In addition, families may decide to use special diets, supplements or other complementary and alternative medicines as therapies based on proposed theories suggesting these reduce symptoms associated with ASD.

It is easy to understand that families become anxious when their children continue to refuse foods, despite offering a variety of foods. Eventually, parents usually give their children foods they know the children will eat. This leads to different and sometimes separate meals for the child, and if behavior is an issue, less participation in family mealtime.

Many children with ASD (especially young children) are followed by a team of therapists who are familiar with autism spectrum disorders as well as with the individual needs of the child and his or her family. The registered dietitian (RD) is an important member of this team. The RD provides an assessment of the child’s intake and growth and works with the family and other team members to develop a therapy plan that includes nutrition and feeding goals. This collaboration between specialists, families, and local/community health-care providers enhances care.

#### Growth

Emond et al. reported no differences in weight, height or Body Mass Index (BMI) in a longitudinal study of children with ASD compared to controls. Growth was evaluated at 18 months and 7 years of age. The majority of children with ASD have growth parameters within normal limits, thus energy needs are usually met even if families report a limited intake. However, adequacy of intake for other nutrients, especially if the child is on a restrictive diet, needs to be evaluated.

#### Nutrient Intake and Feeding Behaviors

Various studies have looked at the nutrient adequacy of diets consumed by children with ASD. Some studies have compared intake with matched controls that are typically developing. Other studies have no controls. In general studies have had small numbers of subjects and age ranges of the populations have varied.

Results from studies with controls have been mixed with results indicating children with autism have nutrient intakes that are below, the same as, or above children without autism. Some of the nutrient intake studies considered food selectivity while others did not so the question of influence of selectivity remains. The studies also may or may not have considered the overall family intake, special diets, and, based on the study date, the diagnosis of ASD may have changed for the study population. A review of research done over the past 25 years has been published, as well as two resource articles.

A very early study in the mid 1980’s found that children, described as autistic, consumed significantly greater intakes of studied nutrients compared to the control group except for vitamins A, C, and fat, but overall diet adequacy was the same for both groups. Parents of the children in the autistic group did report problems with pica, food cravings and eating problems. They also reported a more positive belief in the relationship between diet and behavior and importance of nutrition.

A more recent work in 2008 reviewed 3-day food records for 20 preschool children in a case control comparison.

#### Table 1 - Common Behaviors Features of Children with Autism Spectrum Disorders

<table>
<thead>
<tr>
<th>Inadequate or inappropriate social interaction related to:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Impaired use of nonverbal behavior (e.g., eye contact)</td>
</tr>
<tr>
<td>• Lack of social or emotional reciprocity</td>
</tr>
<tr>
<td>• Inability to read other people’s moods and intentions</td>
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<tr>
<td>• Failure to develop peer relationships</td>
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<table>
<thead>
<tr>
<th>Impaired language and communication as seen in:</th>
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<tbody>
<tr>
<td>• Delayed development of spoken language</td>
</tr>
<tr>
<td>• Inability to sustain a conversation</td>
</tr>
<tr>
<td>• Use of repetitive or idiosyncratic language</td>
</tr>
<tr>
<td>• Lack of make-believe play</td>
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<table>
<thead>
<tr>
<th>Rigidity and perseveration noted in:</th>
</tr>
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<tbody>
<tr>
<td>• Abnormal preoccupations</td>
</tr>
<tr>
<td>• Inflexible adherence to routines or rituals; resistance to change</td>
</tr>
<tr>
<td>• Repetitive movements and activities (stereotypies)</td>
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<tr>
<td>• Preoccupation with parts of objects</td>
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</table>

Note – Not all behaviors are seen in all children diagnosed with ASD.
Nutrient intake was similar for both groups with most consuming more than recommended amounts for most nutrients. The nutrients less likely to reach recommended levels for all children included vitamin A, vitamin E, fiber, and calcium. Sixty percent of the children with ASD regularly took a vitamin/mineral supplement versus 5% of the controls. Parents of children with ASD were more likely to describe their child as picky, having favorite food textures, and resistant to trying new foods. Just over 10% of families with children diagnosed with ASD described their child as a healthy eater compared to 58% of controls.

In 2009 3-day food records were used to assess the nutrient intake of 46 children with ASD and 31 children with typical development. Children with ASD consumed significantly more vitamin B6 and E and non-dairy protein servings, less calcium and less dairy servings than controls. With further exclusion of those with ASD on a gluten-free casein-free (GFCF) diet, the dairy servings did not increase. However, children in both study groups did not meet the DRI for fiber, calcium, iron, and vitamin E and D.

**Food Selectivity**

Many parents report that their children diagnosed with ASD as infants fed well and accepted baby foods, but the transition to table foods was problematic. A recent longitudinal study of children with ASD found that as infants they were more likely to have late introduction of solids and be described by their parents as “slow feeders.” After 15 months of age the parents reported the children had difficulties in feeding and were very choosy.

The primary feeding/nutrition concern reported by parents is “picky” eating. Studies have looked at food selectivity, picky eating, food refusals and rigidity in children with ASD and some studies have compared these behaviors to typically developing controls. A review of these studies has been published suggesting that selectivity is a significant problem but the small numbers, lack of control groups in some cases and a working definition of selectivity impact the degree to which these behaviors are present.

A 2010 study presented a definition of selectivity across 3 separate domains: food refusal, limited food repertoire, and high frequency single food intake (HFSFI) with suggestions for assessment of each domain. Working within the proposed definition the study found children with ASD exhibited more food refusals than the typically developing controls. Children with ASD also had more limited food repertoires and this led to an inadequate intake of a greater number of the 8 measured nutrients but both groups exhibited low intakes for selected items. There was no significance related to either group in regard to HFSFI. Table 2 lists behaviors that may relate to selective eating patterns.

Foods frequently reported in the diets of children with ASD include dry cereal (without milk), crackers, chicken nuggets, pizza, bread, hot dogs, and plain pasta. Children may eat few vegetables and fruits and refuse soft, smooth textures e.g., mashed potatoes and cooked cereal. Over time, some children may narrow their accepted foods to fewer than 10 items. Within that restriction, the child may allow only certain brands or methods of preparation. Finger foods may be preferred versus those using utensils. Since research does suggest that food selectivity is a problem and that it may be related to food texture issues, a feeding team evaluation at an early age may be helpful.

**NUTRITION ASSESSMENT**

Due to questions related to nutrient intake and food selectivity, children with ASD and their families should be able to request a nutrition evaluation with the RD for an individualized assessment and recommendations. As noted earlier, this assessment may be a part of a team evaluation and results can be included as part of therapy goals and/or as individual nutrition goals for a child related to intake, sensory issues, and or behavior of each child. If children participate in an early intervention program or special education, nutrition goals can be incorporated in the child’s Individualized Family Service Plan (IFSP) or Individualized Education Plan (IEP).

The components for nutrition assessment of a child with diagnosed or suspected ASD would include the usual an-

<table>
<thead>
<tr>
<th>Table 2 - Possible Selective Food Patterns Related to Autism Spectrum Disorders (ASD)</th>
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<tbody>
<tr>
<td><strong>Behavior associated with ASD</strong></td>
</tr>
<tr>
<td>Need for routine, difficulty with transitions</td>
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<tr>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Increased sensitivity to texture, taste, temperature, and smell</td>
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<tr>
<td></td>
</tr>
<tr>
<td>Easily overwhelmed or overstimulated</td>
</tr>
<tr>
<td>Short attention span</td>
</tr>
<tr>
<td>Impaired social interaction and communication skills</td>
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</table>
thorpenometric, dietary, feeding development and behaviors, and any biochemical results. A previous NUTRITION FOCUS article has addressed nutrition assessment guidelines for children with special health care needs.\(^9\) For this population, additional assessment areas should be addressed (See Table 3). These include specific information in the following areas.

**Lead exposure** – Since children with developmental delays, including ASD, have an extended period of oral motor play (“everything goes into their mouths”), lead screening should be done, even without evidence of pica.

**Medication-nutrient interactions** – Many children with ASD, especially as they get older, take medications such as stimulants (Ritalin), anti-convulsants (Dilantin, Tegretol), selective serotonin re-uptake inhibitors – SSRIs (Zoloft, Prozac), and anti-psychotic medications (Haldol). These medications can impact a child’s nutritional status by decreased appetite and growth (stimulants, SSRIs), impaired bone mineralization (some anti-convulsants), increased appetite and weight gain (anti-psychotics), and GI symptoms (SSRIs and anti-psychotics).

**Alternative nutrition therapies** – including special diets (gluten-free, casein-free; anti-fungal); vitamin/mineral supplements; herbal products; other compounds.

**Oral health** – Toothbrushing and good oral hygiene may be difficult for some children with autism spectrum disorders. Good oral hygiene is essential and may help with oral desensitization. Therapists (e.g., physical, occupational, or speech) should be consulted for techniques to aid in oral-facial desensitization. In addition, dental care by specialists with experience with children with autism and related disorders may be needed.

**GI symptoms** – GI symptoms, including constipation, diarrhea, and reflux, are often reported in children with ASD and can affect intake and nutrition status. In addition, difficulty communicating pain and/or discomfort can contribute to behavior and other problems. Research about specific causes and interventions for GI disorders continues.\(^12\) See also RESOURCES 6,7 and 8.

**NUTRITION INTERVENTION STRATEGIES**

**Use of a multivitamin/mineral supplement**

Since many diets of children with ASD indicate a need for multivitamin/mineral supplements, it can be a challenge to get the child to take them as something “new.” Families are the best sources for developing these strategies to incorporate supplements although teamwork with the RD and therapist may be helpful. Different forms can be considered for the best option, e.g., chewable, liquid. Supplements can also be crushed or dissolved in liquids for administration. Behavioral strategies including pairing the vitamin with a favorite food or activity, or treating it like “medicine” (for children who accept medication) can be considered depending on the individual child.

**ASD and “Picky” Eating Behavior**

The most frequent nutrition/feeding goal for families is to have the child accept a wider variety of foods. The usual “offer a variety at regular meals” is not helpful; they’ve already tried that approach. When trying a new food or change in diet, families often end up dealing with a significant tantrum or other negative behavior. Use of a behavior-based approach with incorporation of similar interventions as those used in the child’s overall program, suggests a more positive outcome. This is described in the box on page 6. See also the reproducible handout for families included with this issue.

**Techniques that may work**

**Avoid overwhelming a child.** It is often helpful to keep mealtimes constant or to make small, gradual changes. For example, if a meal must be eaten in an unfamiliar place, ask the family to take the child’s usual plate and utensils along. Offer small servings of a few foods; some of the children in the study described in the box on page 6 ate more when only a few foods were offered in age-appropriate portions. If a new food is being introduced, offer it along with foods the child already likes. Since food preferences seem to remain relatively constant, offering at least one preferred food may help to ensure that something is eaten and be reassuring to the family and children.

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**Table 3 - Nutrition Assessment Components for Children with Autism**

<table>
<thead>
<tr>
<th>Component</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Anthropometric data – Length/height, weight, weight/length or BMI</td>
</tr>
<tr>
<td>• Dietary history/ current food intake</td>
</tr>
<tr>
<td>• Feeding development history</td>
</tr>
<tr>
<td>• Feeding behaviors — current and past</td>
</tr>
<tr>
<td>• Biochemical data, including screening for lead exposure</td>
</tr>
<tr>
<td>• Medications and drug-nutrient interactions</td>
</tr>
<tr>
<td>• Oral health status and risks</td>
</tr>
<tr>
<td>• Use of alternative nutrition therapies and the family’s perception of</td>
</tr>
<tr>
<td>the therapy. Include:</td>
</tr>
<tr>
<td>▪ Special diets</td>
</tr>
<tr>
<td>▪ Vitamin-mineral supplements</td>
</tr>
<tr>
<td>▪ Herbal or other products</td>
</tr>
</tbody>
</table>

Nutrition Focus Vol. 25 #4 5 July/August 2010
A classroom-based behavior approach for food acceptance

A study of food behaviors of children with ASD was conducted in a special education preschool setting. Children, ages 4-5 years with ASD, participated in a single-case design intervention study. Although they were growing appropriately, they were at nutritional risk because of feeding problems that included food refusal and selectivity.

Classroom teachers, parents, and the RD identified the target behaviors: food refusal and selectivity. Goals were to increase variety to include a sandwich and fruit. The teachers and the RD developed specific interventions for each child that were consistent with existing behavior programs; these were carried out in the classroom during lunchtime over four weeks. The interventions included gradually introducing new foods, repeated exposure to new foods, and verbal reinforcement for touching, smelling or tasting a new food.

Behavior changes were monitored in a number of ways, including a parent questionnaire, teacher report, food records, and videotaped observation. No changes were noted in appropriate (behavior consistent with classroom rules) or inappropriate behavior. Energy intake remained constant or increased, and intakes of preferred foods (beverages, crackers) remained constant throughout the intervention period. Thus, the changes in mealtime routine did not have a negative impact on the children’s eating behaviors, an important finding since clinicians and families often worry that changes to the food pattern of a selective eater may further narrow his intake.

After 2 weeks of intervention, many target responses increased. This is similar to data for children who are developing typically—many exposures to new foods were required before foods were accepted. Changes in food acceptance were “step-wise.” For example, one child would not allow fruit on the table at the beginning of the study period. By the end of the 4 weeks, he would pick up a piece of fruit. After the study was complete, he ate a piece of fruit.

The results of this study and other published data generated strategies for interventions. See Jamar’s story below for one example of the classroom-based intervention. A reproducible parent education handout was developed and is included with this issue of NUTRITION FOCUS.

Story of Jamar

Jamar is a 5-year old boy with autism who has behavior problems around eating. His family was concerned because he was very disruptive at mealtime and refused to try new foods. He does not usually feed himself, but when he does, he tends to “overstuff” his mouth. His family decided that the first goal would be for Jamar to sit at the table; this would allow them to go out to eat.

Jamar’s plan at school included access to a favorite book as a reward for specific behaviors. His family agreed that it would be acceptable for Jamar to have a book at the table. Jamar was given access to a book after sitting at the table for 5 minutes. Then, the book was given after 10 minutes. The amount of time was increased until Jamar was sitting at the table for the amount of time that the other students were expected to remain seated, and access to the book was gradually decreased. Jamar’s school and family will use the same approach for the other target behaviors.

Introduce foods in forms that are similar to foods the child already eats, and make gradual changes. For example, for a child who eats crackers but refuses to eat bread: Offer sandwiches made with crackers. Then, offer sandwiches made with toast. Finally, offer sandwiches made with bread.

Expect slow changes, but do expect changes. The study demonstrated that increased exposure to new foods and manipulation of foods offered is effective for some children. Progress toward food acceptance, however, may require a greater number of intervention-based steps for children with autism than for children without autism. Research with children who are developing typically indicates that as many as 10 or 15 exposures to an unfamiliar food are needed before a child will taste it. For a child with ASD, who requires more time for transitions to new things, more exposures may be needed. This can be frustrating for families and clinicians. It is helpful for everyone to adjust expectations and be patient as the child makes slow progress.

Design interventions that are consistent with other effective approaches for the individual. If a child’s education plan includes prompting and praise, this is likely to be effective at mealtimes as well. The technique should be appropriate to the child’s developmental age. Interventions can be incorporated into a child’s educational goals e.g., Individual Education Program (IEP) or Individualized Family Service Plan (IFSP). This requires coordination between the school, family, and the RD, but often helps to balance nutrition with social situations.

Techniques that probably will not work

“Bribing” a child to eat a food is not an effective long-term approach. Offering a child a preferred food (for example, candy) as a reward for eating a non-preferred food (for example, vegetables) teaches the child that he needs a reward to eat vegetables.

Forcing a child to “take a bite” of a non-preferred food is not effective. This can create negative associations with food and eating. It also takes control away from the child.

Families and clinicians may be reluctant to alter the diet of a child with an ASD because of the fear that all foods might be eliminated in the process. The interventions used in the study described on page 6 did not result in decreased intake. Manipulation of part of a child’s diet is unlikely to have a negative effect on eating behaviors, and increased exposure to new foods, along with simple behavior-based interventions, can lead to small positive changes in food acceptance. The classroom seems to be an ideal setting for implementation of interventions for feeding problems. It provides the opportunity for an interdisciplinary approach and utilizes strategies that are already successful for the individual child.

**ALTERNATIVE THERAPIES FOR ASD**

Many nutrition-based interventions have been proposed to treat ASD, although scientific evidence confirming the efficacy of nutrition interventions is not yet available. As RDs, evidence-based practice is of the utmost importance in providing nutrition education and services.

While scientific evidence for the effectiveness of most alternative treatments is lacking, sophisticated marketing, testimonials and unproven claims have prompted many parents to adopt dietary changes and supplementation regimens for their children with ASD. The plethora of information available to parents and families on the Internet provides added challenges to RDs and other health care providers. Understanding the nature and scope of alternative therapies is important in providing the best quality family-centered care.

RDs and other health professionals must be able to evaluate information about alternative nutrition therapies for ASD. See Table 4. Families who are searching for effective treatments for their child may not discriminate between anecdotal reports and research-based scientific evidence, and much of the marketing material is presented as “scientific.” Open dialogue between the RD and the family is critical, as is understanding of the family’s desire for an effective treatment.  

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**Table 4: Evaluating Nutrition/ASD Research.**

<table>
<thead>
<tr>
<th>Criteria for a good study</th>
<th>Implication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample size</td>
<td>For statistical validity, sample size must be adequate, i.e., producing sufficient data for analysis.</td>
</tr>
<tr>
<td>Subjects are randomized</td>
<td>Randomization minimizes bias. Selectively enrolling participants, or using subjects with a certain belief system can skew data results.</td>
</tr>
<tr>
<td>Comparable subjects</td>
<td>Subjects should be as similar as possible to limit any confounding factors that may affect the outcome, such as diagnosis*, school program, etc. Intervention and non-intervention subjects should be matched before entering the study. (*Standardized diagnosis is key in behaviorally-defined disorders).</td>
</tr>
<tr>
<td>Use of a placebo</td>
<td>A placebo is necessary in order to compare the effects on the subjects with treatment to those not receiving treatment. The placebo should be indistinguishable from the treatment. The “placebo effect” can be very powerful.</td>
</tr>
<tr>
<td>The study is double-blinded</td>
<td>The most unbiased data is collected when the participants (child, parents, teacher) and the assessment team do not know the intervention.</td>
</tr>
<tr>
<td>Study results (“outcome measures”) are valid</td>
<td>Measuring behavioral change must be carried out using objective methods/tools.</td>
</tr>
<tr>
<td>Use of appropriate statistics</td>
<td>Results should be interpretable by other researchers, and should be valid without exaggerating the meaning of the observed results</td>
</tr>
</tbody>
</table>

Adapted from: Hyman SL, Levy SE, Autistic spectrum disorders: When traditional medicine is not enough; REFERENCES 13 for additional information.

**Gluten-Free &/or Casein-Free Diet**

The casein- and/or gluten-free (GFCF) diet is based on the “opioid excess theory.” This approach is based on the hypothesis that children with ASD have inadequate gluten- and casein-related digestive enzymes and a “leaky gut,” which leads to the absorption of biologically active casein- and gluten-derived peptides (casomorphines and gluteomorphines). These polypeptides cross the intestinal brush-border and, according to the theory, act as opiates in the brain ultimately resulting in many of the behaviors seen in children with ASD. These mechanisms have not been conclusively confirmed. A 2006 survey indicated that about 27% of families had implemented an alternative diet for their child with ASD. Information about implementing the diet is available to families, especially on the Internet.

Although there are anecdotal reports of the diet’s effectiveness, systematic reviews of the literature do not support use of a GFCF diet for ASD. The Specific Carbohydrate Diet (SCD) is another diet that is sometimes used. It is...
more restrictive than the GFCF diet, with the elimination of grains, dairy, sucrose, and complex carbohydrates.

Because elimination diets are potentially harmful in young children, there is concern that such treatment, if implemented without appropriate guidance, may result in compromised nutritional status. Nutrients of concern with the GFCF diet include calcium, vitamin D, iron and protein. However, because of the elimination of most fortified foods (which typically contain gluten and/or casein), no nutrient can be ruled out for possible inadequate intake. Additionally, given that children with ASD tend to be more selective eaters than their peers without ASD, nutrition-related concerns should remain a priority.

The degree of social separation in maintaining a special diet may take its toll as well. “Going out” can become more difficult for parents and their children; there are fewer options for food at parties, school and with relatives. Additionally, the cost of alternative nutrition therapies/supplements can be very high, sometimes crowding out other important purchases such as groceries, housing, medications, and other therapies.

**Food Additives, Preservatives, Colorings**

Although some parents choose to restrict their child’s intake of food additives and/or colorings for treatment of ASD, there is no evidence to support this measure. The removal of food colorings from the diet has been anecdotally associated with a decrease in hyperactivity (the Feingold Diet), but this it is not supported by research. Limiting foods with additives can be very difficult. Families who choose to implement the Feingold diet should receive guidance to ensure their children receive adequate nutrition.

**Nutrition Supplements**

**Vitamin B6 & Magnesium** – Mega-doses of vitamin B6 (pyridoxine) have been proposed as to treat due to the vitamin’s role in the production of certain neurotransmitters; dopamine, GABA (gamma aminobutyric acid), serotonin, dopamine, epinephrine, norepinephrine. In most cases, vitamin B6 is given along with a supplement of magnesium, in order to counterbalance the deficiency of magnesium that a mega-dose of B6 can induce. The late Bernard Rimland, who founded the Autism Research Institute, proposed this therapy approximately 33 years ago. He and others claim that “the benefits of B6 and magnesium for people with autism vary considerably but may include: improved speech, better sleep habits, greater attention span and eye-contact, reduced hyperactivity, diminished irritability, less self-stimulation and improved general health.” However, systematic reviews have concluded that there is insufficient objective evidence to recommend vitamin B6 with magnesium as a treatment modality for children with ASD.

“Therapeutic dosages” of vitamin B6 for children vary. The average amount taken per day in studies purporting the use of vitamin B6 was 8 mg per pound of body weight. For a 60-pound child, this would be 480 times the DRI (1.0 mg/day for a ten-year old). The tolerable upper limit (UL) for vitamin B6 has been set from 30 to 80 mg per day to cover the age range 1 to 18 years. Overall toxicity of the vitamin has been shown to be rare, and the Cochrane review found no adverse effects in the one 10-week study that met inclusion criteria. However, acute doses have been known to cause ataxia, loss of fine motor control, changes in gait and peripheral neuropathy in humans.

Super-Nu Thera® is a megavitamin mixture designed by Rimland, with an emphasis on vitamin B6 and magnesium plus 14 other vitamins including A, D and E, vitamins C, B1, B2, B12, zinc, magnesium, manganese, selenium, calcium and folic acid (incomplete list). Parents and caregivers do not always realize that the components in multivitamin mixtures can be repeated in other supplements their child is taking; the awareness that vitamins and minerals can be toxic at high doses should not be taken for granted. Families should be counseled as to the tolerable upper limits (ULs) now set for most vitamins and minerals, and should be encouraged not to exceed these levels.

**Omega-3 fatty acids** – Supplementation with omega-3 fatty acids (alpha-linolenic acid – ALA, eicosapentaenoic acid – EPA, and docosahexaenoic acid – DHA) is common. No mechanism has been identified, and there is limited evidence to support efficacy. Potential risks associated with omega-3 fat supplementation include GI issues and, more seriously, inhibition of platelet aggregation. Depending on the type of supplement used, vitamin A toxicity may be an issue.

**Other Supplements** – Other supplements have been promoted for use with ASD, and thus-far, most of the research is inconclusive. Some of the supplements used include vitamin C, dimethylglycine (DMG), folate (and related nutrients), melatonin, and probiotics. Supplements which are promoted to support immune function include CoEnzyme Q10, zinc, vitamins A, C and E, Beta Glucan and colostrum. Vitamin A and zinc have known toxicities and should be used with care, if at all.

As a result of the hypothesis between ASD and immunity/allergy, some commercial laboratories promote assays to measure circulatory food-immune complexes (such as IgG and IgE antibodies to food antigens). Based on this immune testing, other companies promote nutrition supplements geared towards the treatment of ASD. These products are marketed to parents and caregivers of children with ASD without research to substantiate their claims that children
with autism have immune system abnormalities, heavy metal toxicity and/or digestive tract overgrowths of yeast and/or bacteria. Despite the powerful appeal of an effective treatment, there is little evidence to substantiate claims of autism treatment with nutrition supplements.

Working with Families

The impact on families regarding the potential for treatment with supplements is very powerful. Parents are targets of unsubstantiated marketing. They may be overwhelmed, attracted to simple explanations of causality or to an approach that they perceive as ‘natural.’ Because little negative information/data exists on the vast majority of products on the market, parents may perceive that no harm may be inflicted by their efforts at alternative therapies, especially when they are biologically-based and/or not viewed as pharmacologic.

Most studies and “evidence” of effective nutrition intervention in children with ASD are inconclusive. Yet, information on alternative therapies is widely available. Many parents are willing to try anything to effect change in their child’s behavior. Parents need support if they choose to implement an unproven treatment modality. See Table 5.

As nutrition professionals, we can offer:
• Evidence-based information regarding nutrition inadequacy and toxicity
• Respect for the family’s perspectives, values, and decisions
• Nutrition guidance for the child’s appropriate growth and development
• Guidance in how to evaluate “research studies”
• Help in managing behaviors related to food and mealtimes
• Caution regarding setting expectations for unproven treatments
• Assistance in setting up and evaluating alternative treatment within safe guidelines

SUMMARY

With the increased incidence of ASD in the pediatric population, RDs and other health care professionals will be asked to help families with eating and feeding challenges in these children. Understanding the basis and nature of the behaviors and food selectivity will assist in providing appropriate nutrition intervention. By working with other service providers and incorporating behavioral and educational approaches, we can support families in their efforts to maintain optimal nutrition as well as improve food acceptance and eating behaviors in their children with ASD.

Table 5 – Guidelines for Using Alternative Nutrition Therapies in ASD

<table>
<thead>
<tr>
<th>Guidelines for Using Alternative Nutrition Therapies in ASD</th>
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<tbody>
<tr>
<td>• Strongly encourage the involvement of the child’s pediatrician or primary care provider</td>
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<tr>
<td>• Be knowledgeable about the potential side effects of the treatment</td>
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<tr>
<td>• Advise family of the known dangers of over-supplementation</td>
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<tr>
<td>• Evaluate the child’s intake to ensure it is not deficient in macro- and micro-nutrients</td>
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<tr>
<td>• Make only one change at a time (including behavioral treatment interventions)</td>
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<tr>
<td>• Evaluate responses to treatment that can be measured</td>
</tr>
<tr>
<td>• Use evaluators that are blinded to the treatment approach (e.g., teachers)</td>
</tr>
<tr>
<td>• Keep lines of communication open; encourage the same with primary care provider(s)</td>
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Adapted from: Hyman SL, Levy SE. Autistic spectrum disorders: when traditional medicine is not enough; Contemporary Pediatrics 2000;10:101.25

Case Study - Nicholas

Initial Evaluation

Nicholas, 20 months of age, was first seen at an early intervention center (EIC) due to a recent diagnosis of autism. A nutrition assessment by the RD was included as part of the initial evaluation because of concerns about a limited intake and difficulty transitioning from pureed to solid foods. A feeding therapist observed the nutrition evaluation and scheduled a formal feeding evaluation.

Interdisciplinary assessment and plan

After the evaluations Nicholas’s interdisciplinary therapy plan was developed for EIC services. He qualified for weekly speech and motor (occupational and physical) therapy services and was enrolled in the CUBS program (Communication, Understanding, Behavior, Socialization). CUBS included intensive classroom services through two 2-hour classes each week. A variety of strategies are used (e.g., developmentally appropriate practices, naturalistic instruction, Applied Behavior Analysis, DIR/Floortime). The classroom staff includes educators, speech therapists, and occupational therapists. Family support is provided through home visits and counseling sessions, and support is provided to families as children transition to school-based programs at age 3 years. In addition, Nicholas enrolled in a university research study which provided 30 hours of therapy each week. Nicholas’s family was eager to take
advantage of as many opportunities as possible to help with his development.

Growth
Nicholas’s weight, length and weight-for-length are shown in Figure 2 on page 11. In general all parameters have followed the same pattern. While weight-for-length is above the 90th percentile this pattern has been consistent over time. There have been no concerns about Nicholas’s growth.

Intake
Nicholas’s mother reported that he had difficulty latching on to the breast so was bottle fed soy formula. Solids were introduced without any problems at 7-8 months of age.

At the initial contact with the RD, Nicholas’s primary source of nutrients was formula (18-22 ounces of a toddler soy formula) from a bottle. His family tried to introduce cow’s milk a number of times, but Nicholas refused to accept even small amounts of milk mixed with formula. Nicholas eats “stage 2” baby foods (peas, green beans, squash, sweet potato, and banana custard), whipped yogurt, and Cheerios. Previously he ate applesauce and pears but refuses them now.

Nicholas was particular about routines. For example he would only eat Cheerios if they were placed in the round section of his booster tray, and he needed to see food come from the jar; strained food from a bowl was not acceptable.

Assessment and Plan
Although limited, Nicholas’s food pattern allowed for growth and met the Dietary Reference Intakes (DRI) for boys his age and size for energy, protein, vitamins, and minerals. His formula was a good source of vitamins and minerals. His family used positive methods to accommodate his selective eating pattern. For example, they recognized the colors, textures, and temperatures of foods Nicholas accepted, and tried to increase variety using these parameters. They offered meals and snacks at appropriate intervals, and involved him in the family meal, even if he did not eat the same foods.

Nicholas’s family wanted to ensure that his intake was adequate and wanted help increasing the variety of accepted foods. Initial recommendations were provided with anticipation of the feeding assessment and potential therapy.

• Continue to have regularly scheduled meals and snacks (e.g., every 2-4 hours) to allow Nicholas ample access to food/drink and also time to get hungry in between. Use a routine at the beginning of each meal/snack, so Nicholas knows it is “time to eat.” Formula should be considered as a meal or snack.
• Offer a choice at meals – for example, pureed peas or pureed sweet potatoes
• Introduce new foods at snack time (vs. mealtime) and allow Nicholas to play with the new food. Because he is eating enough at meal times (and drinking formula), it is not critical if he eats any of the “new snack” foods.

Follow-up evaluation
Nicholas was seen again at age 27 months. He continued to receive therapy through the early intervention program and the research study.

Growth and Nutritional Status
Nicholas continued to be a “selective eater.” His primary nutrient source continued to be a toddler soy formula from a bottle, though he started to accept some milk. Accepted foods were some “stage 2” baby foods, chicken nuggets, and some “snack” foods (Cheerios, Kix, and graham crackers). He was sensitive to shape (round), color (tan/brown), and taste, texture, and temperature of foods. Nicholas’s family provided exposure to a variety of foods without pressure to eat the food. For example, his mother would talk about what was on her plate. They would eat out at the same restaurants, to make the social situation as comfortable as possible. Nicholas’s intake continued to meet his nutrient needs with the formula providing the majority of vitamins and minerals. His intake provided for a continued growth pattern.

Assessment and Plan
Two primary issues were identified by Nicholas’s family at this visit: 1) transition from bottle to cup, and 2) expanding Nicholas’s food repertoire.

The therapists with the research study helped Nicholas’s family develop a behavior plan to discontinue use of the bottle. The RD and Nicholas’s family identified together some specific goals (i.e., which bottles to eliminate first, foods to offer to replace the nutrients from formula/milk, and ways to add milk and other fluids to meals and snacks.)

Recommendations for expanding the variety of foods Nicholas would accept were similar to those made at the previous visit:
• Continue to offer routine meals and snacks
• Continue to offer choices
• Continue to work with the feeding therapist to expose Nicholas to different foods, tastes, and textures

Follow-up evaluation
At 33 months of age Nicholas continued to receive therapy (speech, motor and education) through the early intervention center, attended CUBS, and participated in the
Growth and Nutritional Status

Nicholas's growth continued along established channels. (See Figure 2). Nicholas's intake was adequate for energy, but his intake was not adequate for calcium, iron, and vitamin D. Recommendations for increasing his intake of these nutrients included the following:

- Additional 4-8 ounces milk to provide calcium and vitamin D
- 1-2 servings yogurt or cheese to provide calcium
- ½ to 1 serving meat, black or pinto beans to provide iron
- Multivitamin with iron supplement

Over 6 months, Nicholas's food pattern changed. He made the transition from using a bottle to drinking independently from a cup. While a desirable change, the transition resulted in a decreased milk intake. Nicholas's food choices expanded to include more crunchy foods (chips, crackers, some dry cereal) and lots of chicken nuggets. He continued to be very selective about foods – for example, chicken nuggets were eaten warm, but not hot. If a food did not meet his preference, he refused to eat anything else at that meal.

Nicholas learned to feed himself, though his mother noted he would be distracted after 2 or 3 bites. These positive changes to Nicholas's intake were made with considerable work from family and multiple therapists, and required a formal intervention plan.

Assessment and Plan

Nicholas was very rigid around food choices (flavor, texture, temperature, color, etc.) and his food preferences were strong. His family continued to work to expand his food repertoire. They exposed him to a variety of foods without pressure to eat them, provided choices to him to allow some control, and were sensitive to his preferences and needs. They accommodated his preferences when needed, but also worked to prevent extreme food jags.

At this visit, the overall plan for Nicholas was to help with the transition from the early intervention program to the public school system. He would continue to receive intensive therapy services from the research program for 5 more months.
It was expected that Nicholas would continue to need feeding therapy and a focused approach to further expand his food repertoire. Often, this requires coordination between the family, school, and other therapists, including feeding therapists. As his family developed a plan for transition to the school district, several approaches were considered. Because meal- and snack-time continued to be a main stressor in family life, they wanted to get as much help as possible but needed to balance Nicholas’s therapy and goals with limited time and energy during a stressful transition. Feeding therapists were not available through the school district, so the family planned to hire one and implement a plan similar to the following:

1) Nicholas’s family will identify desired food
2) Feeding therapist develops some strategies to familiarize Nicholas with the food and its sensory properties, and works with Nicholas individually
3) Nicholas’s school offers the specific food to Nicholas at snack times.

In addition, Nicholas’s family was encouraged to continue with the strategies they have already implemented, including:
• Offer routine meals and snacks.
• Offer choices at meals (e.g., Honeycomb or Kix)
• Expose Nicholas to a variety of foods – talking about them, reading stories about them, looking at them on others’ plates, etc., without pressure to eat the foods.

**Comments**

Nicholas’s progress was slow. The transition from pureed foods to a limited repertoire took nearly two years (10 months of intensive effort by his family, then 13 more months with focused feeding therapy). His mother noted that eating/feeding is constant work. She “rotates” what Nicholas eats, and what he eats from, so that he does not get “stuck.” For example, if she does not change the specific cup, color, or type of cup regularly, Nicholas will refuse to drink from a cup. If she offers chicken nuggets from McDonalds too many meals in a row, he will refuse to eat them.

Nicholas’s story also illustrates one of the realities that families face – the need to prioritize therapy goals because of limits on time and energy. Nicholas received about 40 hours of therapy per week – and even if his parents’ energy had been limitless, not all goals could be addressed in that amount of time. Communication between members of the interdisciplinary and interagency team helped to create a consistent, focused therapy plan.

RDs can help families by recognizing that progress will likely be slow. It can be difficult to see changes day to day and families may become frustrated. Health care professionals can remind the families when changes are made from one contact to the next to show the child’s progress. Families may be reassured by evidence that indicates their child’s nutrient needs are being met (e.g., growth records, diet record analyses).

**REFERENCES**


RESOURCES (PROFESSIONAL AND FAMILY)


2. My Child’s Map to Services - Family Voices of WA, WA State Title V and “other” Washington State Parent organizations worked together to create My Child’s Map to Services a template for families. The tool serves as a quick reference guide for families just receiving a new diagnosis of Autism for their child. This tool is for parents wondering about what to do next. It is available in English, Cambodian, Spanish and Korean. Available at http://www.familyvoicesofwashington.com/MyChildsMap.pdf

3. Autism Internet Modules - The Autism Internet Modules were developed with one aim in mind: to make comprehensive, up-to-date, and usable information on autism accessible and applicable to educators, other professionals, and families who support individuals with autism spectrum disorders (ASD). Written by experts from across the U.S., all online modules are free, and are designed to promote understanding of, respect for, and equality of persons with ASD. Available at http://www.autisminternetmodules.org/

4. Autism Spectrum Disorders Knowledge Path - an electronic guide to resources about screening for autism spectrum disorders, diagnosis, treatment and intervention, communication, education, vocational challenges, and impact on family life. The knowledge path, produced by the Maternal and Child Health Library, contains information on Web sites, publications, distance learning resources, databases, and social media. It is intended for use by health professionals, educators, researchers, policymakers, and families and will be updated periodically. Available at http://mchlibrary.info/KnowledgePaths/kp_autism.html


