Registered Dietitians' Insights in Treating Autistic Children

The topic of children and young adults living with autism has once again captured the attention of the mainstream media. Autism is becoming so prevalent in today's public discourse that the producers of popular reality television shows have purchased the rights to a documentary on the topic (1). While, at first blush, this may seem to bring this disorder into the light of public acceptance, it also is a clarion call for health care professionals to ensure that the condition is understood and managed well, and not simply characterized as a personality quirk. This newfound attention is most recently due to the results of the first and largest summary of prevalence data taken from multiple US communities. In a report published by the Centers for Disease Control and Prevention in February 2007—the first published results from the organization's Autism and Developmental Disabilities Monitoring Network—researchers suggest that approximately one in every 150 children in the United States has autism or a closely related disorder. The number of children apparently affected—560,000 nationwide if the statistics are reflective of all 50 states—makes autism now more than ever a "major public health concern" according to Marshalyn Yeargin-Allsopp who conducted the survey (2).

Children afflicted with autism appear to suffer gastrointestinal problems and allergies at a rate that outpaces that of children who do not have autism (3), and parents are seeking nutrition information—from support groups, the internet, etc—on treating these problems.

Autism was first classified by Dr Leo Kanner of Johns Hopkins in 1943; previously the disorder was often confused with schizophrenia. With the increased emphasis on psychoanalysis in the postwar years, the leading view was that the disorder was caused by a lack of affection from "refrigerator mothers," a term for mothers of autistic children based on the assumption that autistic behaviors stem from the emotional frigidity of the children's mothers. In the 1970s, parents began to refute this theory and began pressing researchers to seek other causes, specifically neurological causes. In 1980, autism became an official diagnosis (separate from schizophrenia or retardation), and today scientists are continuing to evaluate the disorder and are considering the idea that there may be multiple autisms (4).

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However, autism—and its various treatment methodologies—continues to be a disorder that is not fully understood. Some researchers have opined that dietary supplements may have beneficial health effects, but their use by developmentally challenged children is cause for consideration because of the "limited evidence of efficacy and safety, the unknown effects on growth and development, and the potential for adverse drug interactions" (5).

Increasingly, parents are investigating supplements and alternative diet strategies, but it should be noted that food and nutrition professionals counseling these families must have access to, and an understanding of, any prescription medications that the child is on. ADA's position paper on providing nutrition services to children with developmental disabilities states that the "dietetics professional's role as an effective member of the health care team is to assess the clinical, biochemical, and anthropometric measurements . . . of the client" (6).

Kimberly Mathai, MS, RD, and Sharon Lemons, RD, offer practical, insightful information on the role of the registered dietitian in educating parents and helping them select the best treatments for their children. Mathai is the author of *The Cancer Lifeline Cookbook* and her special interests include assessment and guidance for persons living with cancer and nutrition programs for persons with developmental disorders. Lemons is an officer for the Dietetics in Development and Psychiatric Disorders dietetic practice group and is the mother of two sons with autism.

Do you agree that the results from the Center for Disease Control and Prevention's Autism and Development Disabilities Monitoring Network do not necessarily suggest that autism is on the rise because the definitions and behavior measures used to define autism have changed over time?

Kimberly Mathai: I think that—like celiac disease—this disorder has been under-diagnosed due to lack of information in the medical community. I continue to meet parents who suspected at early age their children had autism spectrum disorder (ASD), but were told by providers that their children would "catch up" developmentally. Currently, health care providers are more acutely aware of the signs and symptoms of ASD, certainly due to the increasing media exposure of the disorder.

Sharon Lemons: Over time the diagnosis of autism has evolved from a

single disorder to a spectrum of disorders. This may well account for a large part of the increase in number of diagnoses. It's gone from being a disorder nobody would want to have their child diagnosed with because of the stigma of being called a "refrigerator mother" to a diagnosis that will insure your child gets multiple services through the community and school systems. In the past, children were usually only diagnosed if they were severe. Today, many of the children who are being diagnosed are mild. This could very well account for part of the huge increase in the number of children being diagnosed.

It appears that more parents are giving supplements to their children who are autistic. Research studies have shown that supplements may help symptoms, according to the Autism Society of America. Cod liver oil supplements (rich in vitamins A and D) have been linked with improved eye contact of children with autism, and vitamin C has appeared to help in brain function and deficiency symptoms like depression and confusion (7). How do you suggest that food and nutrition professionals council parents on this important issue?

Mathai: At an initial consult, I ask parents to detail what supplements they are providing for their children, and ask them to explain to me what they understand the role these supplements have in their child's therapy program. I then discuss with the parents whether there is good research for their particular use of the supplement, whether they are dosing at adequate levels, and to be alert when using multiple supplements to stay within safe ranges (especially with parents using cod liver oil with other supplements such as vitamins A or D). I don't criticize a parents' choice or pronounce something as "utter nonsense," but help them understand better whether they are making the best choice for their child. Some therapies don't have good documentation but seem to be beneficial. I establish that I am an expert in sorting through nutrition therapies, and that is why they are paying me.

Lemons: I encourage families to look at the research. I talk to them about the difference in peer-reviewed and anecdotal evidence. I also remind parents that raising a child with disabilities is a marathon not a sprint. In short, I remind parents that even though some of these supplements may have a positive effect, using supplements can wear their resources thin (these resources include finances, friends, family, professionals, and emotional support). Parents should also evaluate the research/evidence when making their decisions. I also discuss with them the possibility of toxicity. I discuss with them the supplement they are using then I show them how to determine the upper limits for each ingredient so they can look this information up themselves in the future when they may not have access to my services.

In addition, I encourage them to take a good look at the cost and ask themselves if this is a reasonable price for the ingredients included in the supplement. Some supplements seem to be overpriced. When parents are looking at a particular brand of supplement, I encourage them to read the labels and determine the value of the combined supplements. For example, purchasing the vitamins and minerals separately could save parents a significant amount of money.

According to the Autism Society of America, one of the most common vitamin supplements used in treating autism is vitamin B, which plays a key role in creating enzymes needed by the brain. What role does the RD play in counseling parents on alternative treatments such as enzyme therapy?

Mathai: Enzyme therapy can be helpful, since some researchers have suggested that children on the spectrum may have an inborn error of metabolism: they may lack certain enzymes that break down compounds in foods (eg, peptides in gluten and casein). If these undigested peptides cross the blood brain barrier, they may potentially interfere with cell signal transmissions.

Lemons: See answer to question 1! Remind everyone this is a marathon, not a sprint. Is this something you can manage long term and, if not, do you see a time when this treatment will be able to be discontinued? If you plan to do it permanently, how will you handle emergencies when mom or whoever is managing the diet is unavailable? And, how do you plan to handle this when your child is an adult?

Discuss the importance of food and nutrition professionals' knowledge and awareness of the science behind supplements, enzyme therapy, drug interactions, etc.

Mathai: Parents of children with ASD are very internet-savvy and well-read, but can be prey to undocumented claims for therapies. The RD plays a pivotal role in helping parents to understand what therapies are helpful based on their due diligence in reading literature, attending conferences, and communicating with peers.

Lemons: Registered dietitians need to be knowledgeable about what families are being told, what peer-reviewed evidence is available, and what anecdotal evidence is available. Also, they should pay attention to who is doing the research and see if there is bias involved in the conclusions. For example, there is research on gluten-free/casein-free (GF/CF) causing rickets, and there is a research paper on GF/CF helping with autism, but they aren't multidisci-

plinary. Each is looking for their own conclusion without taking the concerns of the other into account.

How do you suggest food and nutrition professionals convey research findings to parents in a way that they can understand and comprehend what these findings may or may not mean for their family?

Lemons: Much of the research is anecdotal; but that doesn't mean any of these treatments won't yield improvements. Autism research is fairly young. It wasn't until Dr Bernard Rimland of the Autism Research Institute helped dispel the "refrigerator mother" theory in 1964 that researchers started looking at causes other than bad parenting. I feel most of the published research needs more of a multidisciplinary approach. I encourage parents to look at both sets of research both peer-reviewed and anecdotal and makeup their own minds. The professionals who are working with them may disagree with their decision, but our responsibility is not to make the decision. Our responsibly is to provide families with enough information to act upon their decisions safely and with the least amount of negative impact on the family.

Children with autism exhibit restrictive and repetitive behaviors that can influence food intake. Discuss the use of dietary plans, including the gluten- and casein-free diet ("elimination diets") and some advice you typically give to parents on these diets.

Mathai: I ask parents to understand where there are sensory issues relating to food intake, and where there is a misunderstanding of the parental role in the feeding relationship with their children. Before an initial appointment with a client, I ask the parent to keep a food record of what the child is eating. If I note that the child is eating a variety of textures of foods (eg, french fries, ice cream, and pizza), then I discuss with the parent whether there is a texture issue or whether there is a control issue with the child that relates to food. As we know, the feeding relationship between a parent and child is that the parent chooses the food; the child chooses whether or not to eat the food. Often, parents are allowing their children to dictate what, when, and how they eat. I ask the parents to resume their roles as parents in the feeding relationship, serve as good role models in eating a wide variety of foods, and try to have family meals that include foods that all members of the family can eat.

Lemons: I encourage parents to use those repetitive behaviors and devotion to sameness to their advantage. Set up a routine and stick with it. Breakfast is from this time to that time, for example, or everyone eats one protein, one vegetable, and one starch. Glass tables can have something stuck to the bottom that is a graphic of where the plate goes. By putting a graphic on the bottom of the glass, parents could set a routine and teach their child where to place the plate, glass, utensils, etc.

After a family has decided that they want to do a nutritional treatment, I encourage families to ask themselves what their expectations are from the diet/treatment. Either with a health care professional or on their own, I encourage families to look back on their expectations at set intervals. I encourage them to do this either weekly or every other week and list on a piece of paper the current pros and cons of the diet. I want the parents to feel they are in control of the diet/treatment and they have given it an adequate chance, but still be able to discontinue it if they feel it's not working or if it's too overwhelming.

What are the risks in elimination diets? They are viewed largely as risk-free, but is it worth questioning the time, effort, and expense spent in pursuing these diets?

Mathai: The major concern, from my professional viewpoint, is that of any restricted diet: Is the child getting adequate nutrition (macronutrients and micronutrients); is the child eating sufficient quantities of whole foods, including fruits and vegetables, diet-appropriate whole grains, legumes, and appropriate animal protein? An important assessment tool in my practice is computer analysis of food records that shows breakdowns of these macronutrients and micronutrients. This "black and white" record I can share with the parents to help them understand where to address any dietary gaps or deficiencies. As to the efficacy of the gluten-free/casein-free diet, many parents report anecdotally of improvements, both behavioral and cognitive, in their children when on this diet. In addition, other parents have investigated other nutritional approaches to ASD, including the specific carbohydrate diet and the low-oxalate diet; these diets can be appropriate for children with ongoing gut issues.

Lemons: Start eliminating one thing at a time. Make sure they are eating enough kcals, protein, calcium, etc. Even if casein is causing a problem, if you totally remove whatever the child eats and create malnutrition that's not good either. These kids don't fit the mold of "they'll eat when they get hungry." I've seen children go without for 3 days before the parents gave in and gave them what they wanted. Many families are spending countless hours and money buying specialty food and determining which restaurants they can eat at. These diets can have very positive results but it is important to keep in mind that they can also stretch the resources of families that may already be stretching their resources to their very limits.

Whichever dietary treatment is decided upon for a patient, it is important to introduce this change slowly. Is that correct? (Especially considering the repetitive nature of these children?)

Mathai: Initiating the food changes in any nutrition therapy plan is best approached in stages. For example, there is an excellent handout that outlines a 10-week transition to a GF/CF diet, beginning with eliminating dairy foods, finding five GF/CF breakfast foods, finding five GF/CF lunch foods at weekly stages (www.tacanow.com/gfcf_diet_10_weeks.htm).

Lemons: I encourage families to make one change at a time. This will prevent the whole family from being overwhelmed. Learning each of the different diets has a definite learning curve. But if they can establish one new routine at a time then it will make the transition smoother.

I encourage families to use mostly fresh, single-ingredient foods to make it easier on everyone—family members, school personnel, and baby sitters are less likely to make mistakes if you remove the need to read every label.

Both Mathai and Lemons note that the food and nutrition professionals should remember that families are likely working with several health care and education providers, such as teachers, psychologists, physicians, and that families may be overwhelmed with information provided from experts; working in concert with these health professionals benefits the child and the family.

Finally, it's important to urge parents to regularly evaluate the pros and cons of each nutritional therapy, according to Mathai and Lemons.

"We should empower families to give themselves permission to try new therapies while providing enough support to insure a balanced diet," says Lemons. "Then we should empower families to give themselves permission to quit if they feel the diet is having a negative effect. We are responsible for these clients for a short segment of their lives, while parents may be responsible for their children for a number of years—and sometimes—for the rest of their lives."

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