Fundamentals of Dietary and Nutritional Intervention in Autism and Related Disorders

Kelly M. Barnhill, CN, CCN, with an introduction by Bryan Jepson, MD

Dr. Jepson:

Here's what I learned about nutrition in medical school: Zero. If we studied it, it was only a week or so taken out of some other class, and I don't remember it. Most MDs spend very little time on nutrition and the role it plays in health. In medical school we spend our time learning about prescription medicines and how they interact with the body and with biochemistry, so it's not surprising that's how we treat disease. Not only do we not know anything about nutrition, we tend to think of it as unimportant. The dogma that's taught in medical school is that you get everything you need from a typical varied diet. Most of us believe that nutritional supplementation is a way to make expensive urine, just a great way for vitamin manufacturers to make money. When I came into the field of autism treatment, I went back and relearned biochemistry, and I realized by how wide a breach we were missing the boat.

Fifty or sixty years ago, when we had fewer pharmaceuticals to rely on, there was a greater emphasis on nutrition. But I think the public now has a renewed interest in how nutrition affects health, and I think doctors are more aware of its importance. If you look at the articles being published in the medical journals, more and more studies link nutritional abnormalities with health problems.

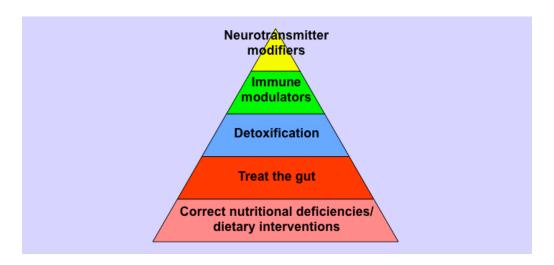
So—this medical school diet dogma—does it make sense? There are several important questions:

- Is the typical US diet healthy?
- Are autistic children at particular nutritional risk, more so than the normal population?
- Are nutritional supplements and special diets necessary, or even helpful, in autism?

The statement, "You get everything you need from a normal varied diet," assumes several things: you are eating a variety of nutritious foods; you have normal digestion; you have a healthy absorptive surface of the bowel; and your body utilizes nutrients appropriately. There are many conditions in which this is known to not be the case (e.g., mental incapacitation, alcoholism, immunocompromise (like HIV), old age, pregnancy, malabsorption syndromes, short bowel syndrome, anorexia, cancer); it's agreed among medical practitioners that these should be treated in combination with nutrition and supplements because these conditions affect how the body utilizes nutrients.

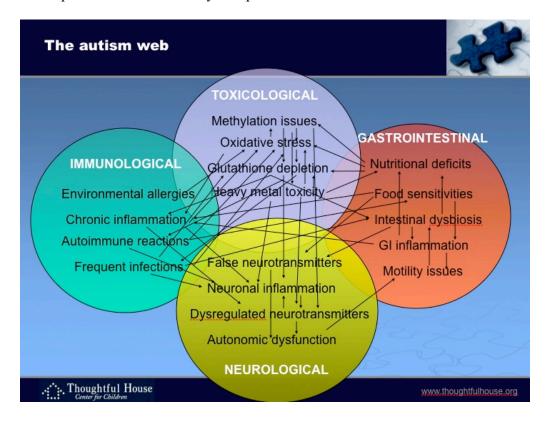
Children with autism have self-limited diets, abnormal digestive enzyme function (they don't break down food appropriately), inflamed gut mucosae (they can't absorb what they eat, i.e., malabsorption), and metabolic abnormalities leading to abnormal utilization of normal levels of dietary nutrients (even if the food is successfully broken down and absorbed, it might not be used effectively). All of these are at-risk criteria. So it makes perfect sense that people on the autism spectrum need appropriate nutritional support as part of their overall treatment plan.

Notice that the foundation of the treatment pyramid is nutritional intervention:



Honestly I think that this should be the foundation of treating all illnesses—our mothers were right; we are what we eat, and if we're eating poorly, then our bodies are not going to work. Most vitamins and minerals act as coenzymes, essential to drive biochemical reactions forward in cellular metabolism. When you have a process in your body that's going from point A to point B, you need an enzyme to drive that reaction; vitamins are coenzymes—they help that enzyme work more effectively. So if you're missing the vitamin coenzyme, the metabolic engine won't move as efficiently. Enzymes and proteins are like the structures kids build with Tinkertoys; vitamins and nutrients hold the structure together, and if you don't have them, the structure falls apart. They're essential because we only get them from our diet—the body can't manufacture them, and without them, it doesn't work normally.

This is a picture of the extremely complicated autism web:



These four organ systems are highly interactive. (And it goes beyond this—there's evidence now that links the endocrine system, and others, to this paradigm.) Everything in this diagram is impaired somehow if there are nutritional deficiencies. Zinc, for example, plays a role in over eighty different enzyme processes in the immune system, the gut, and the brain; vitamin B6 in about 113; magnesium, in four or five hundred. So if you don't have these critical enzymes and nutrients, many key processes will go wrong.

Kelly Barnhill's presentation:

Nutritional status in the US is poor. Our food supply is compromised by environmental issues, including pesticides, PCBs, and other toxins; inferior quality and poorly managed production issues; travel and transit time compromises; and depletion caused by processing and preserving. There is an alarming lack of essential nutrients in our food. In 1910, some 10% of our food was factory-refined or treated with additives; today over 80% of our food supply is refined and treated. Food processing is a major cause of nutrient loss. For example, when whole oranges are turned into orange juice, per 65 calories you lose 100% of the zinc, 74% of the iron, 74% of the riboflavin, 52% of the vitamin B6, 74% of the calcium, and 22% of the pantothenic acid. When an apple is processed into unsweetened applesauce, for every 80 calories you lose 15% of the fiber, 20% of the calcium, 85% of the folic acid, 47% of the riboflavin, 52% of the magnese, and 20% of the magnesium.

'So it's no wonder the average American child's diet is poor—less than 1/3 meet the RDA (U.S. Federal Recommended Dietary Allowance) for fruits and vegetables. It's worth mentioning that the RDA represents the bare minimum—what you need to eat in order not to develop symptoms of deficiency, so please don't use the RDA as a magical formula. A high number of people have low-grade vitamin C deficiency. We rarely see actual scurvy, and we rarely see rickets, but for many people the metabolism and the immune system are functioning just above that line. When they become sick, it doesn't take much for them to slip below the line, and in hospitals we often see cases of symptomatic deficiency.

Reliance on fast food, and heightened calorie intake with low nutrient density, have resulted in a remarkable increase in reports of childhood diseases, including juvenile diabetes, obesity and metabolic syndrome, asthma, and food allergies. People express surprise that our kids are getting fat—it shouldn't be a shock, it's common sense if you look at what they're eating. These diet-driven issues are affecting more and more children in the US and elsewhere. Calculated dietary change and supplementation are necessary for improving overall nutrition for everyone, not just children on the autism spectrum.

What does this mean? It means cleaning up the diet – going organic if possible, local if possible. Eat above and beyond the RDA of fresh fruits and vegetables. Be thoughtful about animal protein consumption. Be thoughtful about fish consumption. Avoid trans fats. Avoid all processed foods, sodas, etc., whenever possible. Use organic whole-food supplements. Use a broad-spectrum multivitamin from a trustworthy source. Use essential fatty acid (omega-3 and perhaps omega-6) supplementation. Consider calcium, magnesium, and vitamin D supplementation, based on dietary needs.

So what does a big-picture healthy diet look like? Whole foods, not from a factory. Natural meats—free-range or organic poultry, grass-fed beef and bison, and natural pork. Free-

range or organic chicken and duck eggs, because regular eggs have lost almost all of their fatty-acid content. These protein sources are important because they're higher in essential fatty acids (primarily DHA but others as well), higher in both Vitamin A and D content, and have higher antioxidant values overall, particularly Vitamin E. They're free from added hormones, antibiotics, pesticides, and other chemicals, and they haven't been exposed to grain feed that's genetically modified. (See: www.eatwild.com and www.organicgrassfedbeef.org.)

Organic fruits and vegetables, best grown locally, are vital because of the pesticide and chemical exposures found in commercial crops (exposure to pesticides has been shown to increase the risk of autism in children (Roberts, et al. "Maternal residence near agricultural pesticide applications and autism spectrum disorders among children in the California Central Valley," *EHP*). They have a higher overall nutrient value in vitamins A, B, C, D, and E as well as minerals like calcium and zinc, and lower levels of heavy metal contamination are documented. The ten most-contaminated commercial crops are peaches, apples, bell peppers, celery, nectarines, cherries, lettuces, imported grapes, and pears, so look for organic varieties when you shop (Environmental Working Group, 2006). In terms of prioritizing your grocery dollars, the ten least-contaminated commercial crops are onions, avocados, pineapples, mangoes, asparagus, kiwi, bananas, cabbage, broccoli, and eggplant (EWG, 2006). (See www.foodnews.org to download a copy of the research and see the 30+ other commercial crops that were tested.)

There's a pervasive myth that fat is bad. This is true for some fats, but healthy fats-organic coconut oil, quality olive oil, and other Omega-9 oils such as macadamia nut oil, avocado oil, and walnut oil—play a vital role in overall nutrition, particularly for children. They're necessary for cognitive development (remember, our brain is made out of mostly fat), cell function, balancing inflammatory responses in the body, supporting the structural, gastrointestinal, respiratory, and immune systems of the body, and these fats are documented to affect behavior and mood swings in both children and adults.

The most important fats are the omega-3 essential fatty acids. Quality purified (due to possible mercury contamination) fish oil and fish liver oil are the best sources (supplementation should be monitored by a clinician). It's important to include both a broad-spectrum whole-body fish oil, which is the best source of EPA and DHA, and a fish liver oil for vitamins A and D. The plant source of omega-3 is flax oil, but absorption of EPA from flax is not as good, and conversion to DHA is significantly limited.

Omega-6 essential fatty acids are also important. Consider supplementation of GLA, which aids in bone growth and development and helps address autoimmune responses such as eczema. Good dietary sources include organic hemp oil, hemp milk, and hemp powders, available at health food stores, and a variety of nuts and seeds. Limit diet sources of omega-6. Omega-6 is a pro-inflammatory, particularly the linoleic acid form, and we eat a lot of it. Vegetable oils and canola oil are high in omega-6.

Omega-9 fatty acids are not "essential," because the body can manufacture them from other dietary fat sources. However, balance among #3-6-9 fats is important, and many children have decreased omega-9 values and increased omega-6 values. Incorporating omega-9 fats in the diet will help balance dietary exposure to omega-6s. Use olive oil in cooking (for sautéing or pan frying only, to avoid oxidation) rather than vegetable or canola oil. Many nut oils, such as macadamia nut oil, hazelnut oil, or avocado oil, are high in omega-9, and they're great for dressings and smoothies.

Organic coconut oil is a saturated fat that's actually beneficial. It has a small amount of

omega-9. It's been noted anecdotally to have antifungal and antiviral properties, and antiinflammatory benefits, as well as improving thyroid function, and immune system support. It can be incorporated in cooking and baking as well as in smoothies. When choosing an appropriate coconut oil product, look for a raw or virgin product, preferably organic.

Include lots of high quality water in your child's diet. Water is always the drink of choice. It's a myth that our children should drink milk or milk replacements (feeding baby cow food to humans doesn't make much sense). Ideally, aim for one ounce per pound of body weight per day. Avoid unfiltered, untested tap water, fluoridated water, and chlorinated water. If you drink bottled water, find a producer/bottler that delivers in glass bottles only, to minimize problems with the chemicals in plastic. (One supplier is Mountain Valley Spring Water.) When offering water to a young child, choose stainless steel (www.kleankanteen.com) or coated aluminum (www.sigg.com) to avoid the plastics in traditional sippy cups and nalgene bottles. Consider home water filters and bottled water options, and choose a product that's a good fit for your family. If you decide to invest in a filtration system, whole-house filters should offer both carbon and reverse osmosis filtration. Kitchen under-counter and counter-top systems are also available with these capabilities. If a whole-house system isn't an option, remember to add filters on showerheads and chlorine filters in bathtubs (www.gaiam.com) to decrease exposure when bathing.

Basic common sense, regardless of which diet you choose: eliminate trans fats and hydrogenated oils (read labels!); eliminate or at least decrease artificial colors, flavors, and preservatives; eliminate artificial sweeteners; limit pesticide exposure (go organic when you can); limit nitrates and nitrites in processed meat products such as bacon and lunch meats; limit sugar, including baked goods, treats, and fruit juices, because sugar feeds yeast; and choose less-processed ingredients and foods (brown rice vs. white rice, natural unrefined sugars, etc.).

Fundamentals About Supplements:

Children with limited diets need supplementation to broaden their range of intake, preferably from organic whole foods. There are many products that are also gluten-, casein-, corn-, and soy- free. Whole food supplements are a good way to get broad-spectrum support from real foods rather than just from synthetically derived vitamins (I like to use both), so I recommend using fruit and vegetable powders, plant-based proteins, etc.

Therapeutic multivitamin and mineral support is necessary and should be determined by a nutritionist to address dietary deficiencies and insufficiencies for each child. This support is maximized with guidance on content, but also on dosing options. Consider calcium support for any child on a casein-free or limited diet. Choose products with high absorption rates (i.e., not Tums). Choose a purity-tested fish liver oil product for natural vitamin A and D as well as a whole-fish oil product (EPA and DHA) for omega-3 essential fatty acid support.

How is it Best to Start With the Diet Options for Autism?

There is no one diet that works for everyone, and you need to consider all dietary intervention carefully, based on your child. Use the interventions discussed here as the foundation, and build wisely upon it. Don't diet hop and shop – work with a knowledgeable practitioner in developing the best diet for your child, one that might incorporate elements from a number of known diets. Stick with the plan – with most advanced dietary interventions, it takes

months (typically a minimum of three) to see significant improvement. Don't throw in the towel--dietary changes are one of the most difficult things we do; most of our children are already on self-restricted diets, and much revolves around food preparation and consumption, so it's easy to be discouraged. Ask for help when you need it! Don't make decisions about diet rashly or in isolation – coordinate all diet plans with your medical care plans to maximize outcomes of all interventions.

Most people start with a gluten- and casein-free (GFCF) diet. Gluten is the protein in wheat, barley, rye, spelt, and kamut; the US oat supply is cross-contaminated with gluten as well. Casein is the primary protein found in milk produced by all mammals, so no goat milk, sheep's milk, or water-buffalo milk on this diet. Eliminating gluten and casein has been documented in both clinical settings and research to benefit a significant number of children with autism. (See Changing the Course of Autism by Bryan Jepson, MD, for references.) Anecdotal positive response varies, but in my clinical practice, approximately 70% of parents report improvement in physical, cognitive, or behavioral symptoms. Not everybody responds, and it's not always profound, but parents typically feel it's worthwhile.

Furthermore, benefit from gluten elimination has been researched in a number of other disease and disorder processes, including celiac disease, gluten ataxia, multiple sclerosis, rheumatoid arthritis, Down's Syndrome, Crohn's Disease, and ulcerative colitis—most of these are chronic autoimmune diseases, so gluten is triggering something in the immune system. Casein elimination has been researched and found to be efficacious in a number of other disease and disorder processes, including asthma, allergies, respiratory mucous production, topical autoimmune responses such as eczema and psoriasis—these are also allergy/immune-related. In my opinion every child on the spectrum should try this diet; it's impossible to predict who will respond. Often the children whose symptoms indicate that they're likely responders don't respond, and vice versa. We simply don't have tests that can make an accurate prediction.

Caveats of successful GFCF intervention: find a knowledgeable practitioner; find a diet support group, perhaps a Yahoo Health Group online; and educate yourself before jumping in headfirst. Learn what both proteins are and where they're hidden in manufactured foods, how to "read between the lines" on package labels, what a quality gluten- and casein-free diet looks like, and develop a go-to-for-help list for support, resources, recipes, and product sources. (Good places to start include www.tacanow.com, www.gfcfdiet.com, and www.autismndi.com.)

Stick with it – you might see positive response to casein removal within 3-5 days; significant response to gluten removal can take six months or longer. We recommend a 90-day minimum GFCF diet trial. Avoid substituting a lot of soy protein for casein protein when going gluten- and casein-free. Soy protein can cause similar responses to gluten and casein, and should be incorporated in the diet sparingly, if at all. Some early scientific evidence suggests it impacts both male and female hormones as well as thyroid function. Fermented soy products (glutenfree soy sauce) and soy lecithin may be used sparingly without the same protein-response risks as soymilk, soy yogurt and soy ice cream.

Base your decisions about further interventions on clinical symptoms and appropriate laboratory analysis, with professional guidance. Does your child crave grapes? Potatoes? Did a recent IgG panel indicate a response to all tree nuts? Does your child have ongoing, severe, and debilitating GI concerns? Coordinate dietary choices with all biomedical treatment and intervention – don't make decisions in isolation! Make a time plan for targeted intervention and stick to it for the best outcome. Develop a plan that best fits the needs of your child and family. Will your entire family follow a new dietary plan? Is your child in a school program that's

friendly to dietary shifts? Are there failure-to-thrive issues that could be of concern? You'll want help when considering these matters.

Other Possible Diets:

Allergy elimination/rotation diets identify food responses aside from reactions to gluten and casein. These can be determined through either laboratory testing or clinical experience. When using one of these diets, someone should evaluate any macronutrient or micronutrient needs that have to be replenished due to eliminating a specific food or food family. Rotation diet protocols allow for coordination of many interventions while addressing nutritional needs. These diets are useful in children with severe food responses, for whom food exposure must be monitored with great care, and they create a means for expanding preferences in children with self-limiting food behaviors.

IgE (immunoglobulin E) tests indicate food allergies by measuring a true histamine response based on exposure to a specific protein. This can be tested through traditional skin-prick testing or blood work (a RAST panel). Reactions to IgE food allergies are typically immediate to within a few hours: flushing, rashes, hives, coughing, wheezing, asthma, GI symptoms (violent vomiting, nausea, diarrhea), and anaphylaxis. These reactions can be treated with histamine blockers if less severe, but respiratory responses/anaphylaxis require epinephrine intervention; in these cases, you must educate yourself and other caretakers, and carry an epipen. Allergy desensitization (allergy shots) might help diminish response over time, but any food trigger should be specifically avoided for the long term.

IgG (immunoglobulin G) tests indicate food Intolerances; they measure a delayed response to a food antibody. These can be tested by means of a blood panel called ELISA. The test might identify specific dietary components to eliminate, which could produce dramatic change in the child. Responses can be immediate or delayed, and might involve the GI system, immune system, and respiratory system. Elimination of the offending food can address GI symptoms, skin conditions such as eczema, and behavioral issues. Intervention can include an allergy elimination/rotation diet developed in conjunction with a treating dietician or nutritionist. Foods to consider first for removal from the child's diet (beyond GFCF) can include: foods with a lot of phenols and salicylates, such as apples, bananas, grapes, and tomatoes; complex carbohydrates, including rice, corn, and potatoes; and plants in the nightshade family, including all potatoes, peppers, tomatoes, and eggplant. The nutritionist will help you to identify appropriate foods to eliminate. This involves removing only that food from the diet for a period of 4-6 weeks, followed by a trial exposure to gauge response, when you offer one reasonable serving twice within one day and monitor the child for a response, then wait three days and challenge again, and then trial in the same fashion a third time. If there is no significant response by then, you can reintroduce the food in rotation.

An important diet to consider was developed in the 1970s by Dr. Ben Feingold, a pediatrician who specialized in allergy and immunology. This diet was based on data on dietary manipulation in asthma and aspirin sensitivity completed at the Mayo Clinic, and was initially targeted at children with ADD and ADHD symptoms. It eliminates all artificial flavoring and coloring, as well as the preservatives BHA, BHT, and TBHQ. The introductory stages severely limit many salicylate foods – salicylates are a subcategory of phenols, which are found in natural as well as artificial foods. This diet eliminates virtually all colored fruits and some vegetables. (These natural salicylates must be avoided in all forms when beginning the Feingold Diet: almonds, grapes, raisins, wine (and wine vinegar), apples (also apple cider vinegar), nectarines,

apricots, oranges, all berries, peaches, cherries, peppers, cloves, plums, prunes, coffee, tangerines, cucumbers, pickles, tea, currants, tomatoes, oil of wintergreen (a source of methyl salicylate).) (See www.feingold.org for more information.)

The Specific Carbohydrate diet was developed over 55 years ago by Dr. Sydney Haas, for managing celiac disease; it was later applied successfully in inflammatory bowel disease (ulcerative colitis and Crohn's disease), by Elaine Gottschall in conjunction with Dr. Haas. It's been used as an intervention for children with autism and bowel symptoms for the past decade. Typically applied in children with severe and ongoing GI symptoms – including both diarrhea and constipation, unvielding fungal infections, and bacterial dysbiosis, it completely eliminates complex carbohydrates from the diet. The principle is to starve out the yeast and bacteria in the GI system and allow the GI tract to heal. (This also allows for repopulation by good bacteria.) The early stages of the diet are based in animal protein, vegetables, and a few fruits, so it can be somewhat difficult to implement for children with IgE-mediated egg and nut allergies, as well as vegan or vegetarian families. There are intensive food preparation requirements, but these can be learned quickly, and when applied appropriately, there is a marked improvement in bowel symptoms in many children. Some children can tolerate goat-milk yogurt prepared for this diet (most can't), and some children can reintroduce complex carbohydrates successfully or move to an alternative complex carbohydrate approach. (See www.pecanbread.com for more information or read Breaking the Vicious Cycle by Elaine Gottschall.)

The low-oxalate diet was researched and applied in autism and related disorders by Susan Owens, MAIS, over the past two-and-a-half years. Oxalate is a substance that can be manufactured by cells in the body as well as by microbes, and it can also be found in foods. In a compromised gut, food-derived oxalates can be absorbed through the GI tract and then collect in other body tissues. The LOD protocol limits oxalate-containing foods as well as providing calcium to bind oxalate and carry it out of the body. It's hard to predict the responders, but children with ongoing diarrhea/constipation issues despite more conventional dietary intervention, children who declined on SCD, and those with growth issues seem to be good responders. Preliminary results indicate a low-oxalate approach might help resolve or address pain associated with urination, frequent urination, penile pain, GI issues such as diarrhea and constipation, gross- and fine-motor delays, photosensitivity, and delayed growth patterns.

The body ecology diet was developed and applied in the treatment of autism by Donna Gates. Used to address ongoing and significant GI concerns, it's applicable for everyone who wants a healthy diet. It replenishes gut microflora and rebuilds GI immunity through a variety of targeted interventions. Built on a health-inductive foundation similar to that discussed earlier, it eliminates gluten and many grains, and on a daily basis incorporates sea vegetables and cultured and fermented foods (coconut water, kefir, cultured vegetables) into the diet. The diet advocates the use of raw (unpasteurized) butter and cream products as well as coconut oil.

I recommend that parents keep a food diary; make it a habit to document everything you alter or introduce, and share the data with your clinician. Make dietary, nutritional, and medical changes in a coordinated fashion. Plot out sequentially what you're going to change, and try not to implement more than one treatment approach at a time. Work with an autism-savvy practitioner to define the best approach for your child. Become an educated consumer. When implementing these changes be an advocate for your child—with your family, with your friends, with your communities, and with your school. Ask for help when you need it, and offer it when you see another parent in need.

Don't be afraid of change! children.	After all, change alone is how	we produce change for these