Escape the Hopelessness. Autism is Treatable.

OVERVIEW

Whether it's biomedical and therapy interventions combined, or simple therapy, autism can be treated...and thousands of children have progressed because of it.

When families and caregivers begin looking into the various treatment options available for autism spectrum disorders, they will be surprised to find that there are many options out there. Unfortunately, what works for some families, may not work for others. Since individuals with autism spectrum disorders are not exactly the same, treatment plans need to be made specific for each individual.

One thing's for sure, autism is not a hopeless diagnosis. To become educated about therapies and providers of therapies and biomedical interventions in your area, we suggest four things:

Join a local support group or local discussion forum.*

Join a national discussion forum. There are many to choose from. <u>Click here for a list of groups.</u>* Find a DAN (Defeat Autism Now) doctor in your area. <u>Click here for a listing</u>.

Find a Generation Rescue Angel in your Area: Click Here.

Check with your child's primary care provider for referrals to private therapists such as speech pathologists, occupational therapists, ABA specialists, etc.

*Check with a DAN doctor, or your child's primary care physician before initiating any biomedical intervention.

DEFINITIONS/SYMPTOMS

Autism is a bio-neurological developmental disability that generally appears before the age of 3.

Autism impacts the normal development of the brain in the areas of social interaction, communication skills, and cognitive function. Individuals with autism typically have difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities.

Individuals with autism often suffer from numerous physical ailments which may include: allergies, asthma, epilepsy, digestive disorders, persistent viral infections, feeding disorders, sensory integration dysfunction, sleeping disorders, and more.

Autism is diagnosed four times more often in boys than girls. Its prevalence is not affected by race, region, or socioeconomic status. Since autism was first diagnosed in the U.S. the occurrence has climbed to an alarming one in 150 people across the country.

Autism does not affect life expectancy. Currently there is no cure for autism, though with early intervention and treatment, the diverse symptoms related to autism can be greatly improved.

According to the National Institute of Child Health and Human Development*, there are five behaviors that signal the need for a doctor** to immediately evaluate a child for autism...

- Does not babble or coo by 12 months of age
- Does not gesture (point, wave, grasp, etc.) by 12 months of age
- Does not say single words by 16 months of age
- Does not say two-word phrases on his or her own (rather than just repeating what someone says to him or her) by 24 months of age
- Has **any** loss of **any** language or social skill at **any** age.

HOW IS AUTISM DIAGNOSED?

Autism is diagnosed based on clinical observation and testing by a professional using one or more standardized tests. Professionals most likely to diagnose autism are psychologists, psychiatrists, developmental pediatricians, and school psychologists. Some of the screenings and tests which may be used in the diagnostic process are: CARS (Childhood Autism Rating Scale), Autism Diagnostic Checklist Form E-2, CHAT (Checklist for Autism in Toddlers), M-CHAT (Modified Checklist for Autism in Toddlers), Pervasive Developmental Disorders Screening Test -2, ADOS (Autism Diagnostic Observation Scale), and ADI-R (Autism Diagnostic Interview – Revised). In addition, parental interview and medical history are taken into consideration.

The current version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) has specific criterion required to make a diagnosis of autism, or a Pervasive Development Disorder.

There are five disorders under the PDD umbrella which include Autism, Aspergers, Rhett's Syndrome, Childhood Disintegrative Disorder, and PDD-NOS (not otherwise specified).

The diagnosis of autism may be made when a specified number of characteristics listed in the DSM-IV are present.

DIAGNOSTIC CRITERIA FOR 299.00 AUTISTIC DISORDER**

*Source: The American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Washington D.C., American Psychiatric Association, **1**994.

A. A total of at least six items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

Qualitative impairment in social interaction, as manifested by at least two of the following:

marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.

failure to develop peer relationships appropriate to developmental level

a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

lack of social or emotional reciprocity

Qualitative impairments in communication as manifested by at least one of the following:

delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others stereotyped and repetitive use of language or idiosyncratic language

lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

apparently inflexible adherence to specific, nonfunctional routines or rituals

stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements)

persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

For information on the diagnostic criterion for Aspergers, Rhett's, Childhood Disintegrative Disorder, and PDD-NOS.

If you suspect your child has a problem, go with your gut. **Do not wait.** Ask your child's physician for a referral to a developmental specialist. If they refuse to give you a referral, call your local or state early intervention center and make an appointment for your child to be screened. You can find a list of state offices at <u>www.nichcy.org/states.htm</u>

RECOMMENDED READING

Children with Starving Brains, Jaqueline McCandless, MD The Out-of-Sync Child, Carol Stock Kranowitz Breaking the Vicious Cycle: Intestinal Health through Diet by Elaine Gottschall Evidence of Harm, David Kirby Unraveling The Mystery of Autism and Pervasive Developmental Disorder: A Mother's Story of Research & Recovery by Karyn Seroussi Special Diets for Special Kids by Lisa Lewis PhD

http://www.mothering.com/sections/experts/arranga-archive.html#to-begin

My child has just been diagnosed with Autism. Where do I begin?

Education is key. Parents are, and must remain, the driving force of our community, the stakes are too high and the issues too sacred to delegate to outside interests. Networking is vital. Parents need to network with more experienced parents, therapists, doctors, school officials and others who will be involved in the care of their child. Time is crucial. While a diagnosis provides entry to certain programs there is no need to wait, in some cases a year or more, before beginning various interventions. Biomedical tests, for instance, while not a diagnostic tool can identify many of a child's underlying etiologies and treatments started.

Treating a child with autism is a large effort involving many professionals and non-professionals. The world of autism is dynamic. It is crucial parents continue to educate themselves and monitor, maintain, and direct the goals of the team for the benefit of their child.

For many parents perhaps the greatest challenge is responsibility. Leaving the warm cocoon of established medicine to embark upon a more promising path requires faith in their own abilities and judgments and an understanding of their unique role as the final authority to help their child.

Autism requires a parent's knowledge to be broad and deep. Questions and answers do not stop at the boundary of a discipline. There are no algorithmic answers. The most effective treatment plans combine a number of disciplines from the biomedical to the behavioral, each with their own range of options, each impacting the other. Parents must also deal with issues involving insurance companies, separation and divorce, state and federal regulations, and legal issues.

Each child is different responding in different ways to identical treatments. Each parent is different as well. Some parents immediately recognize the benefits of and embrace treatments while others are reluctant at best or hostile at worst to even consider the most benign treatments.

My expertise and job as a parent is to investigate, weigh, and implement the best options for my son, be they biomedical, behavioral, or other with an understanding of his unique talents, abilities, constitution and response to various treatments. Together the autism community moves forward replacing ignorance and fear with growing numbers of healthy children.

In May of this year, my two year-old daughter was diagnosed with Autism Spectrum Disorder. She has begun a few interventions already including developmental and speech therapy. She is to start a neurohealth preschool next month. Adding Omega 3-6-9 organic formula fatty acids to her diet has greatly reduced the amount of frustration that appears to be her constant companion. Also, a vitamin and iron supplement was added. What words of advice do you have for us? What is the rate of autism in children who are unvaccinated?

My heart goes out to you autism can be a devastating diagnosis. I admire you and your husband's decision to move forward. There will be difficult days ahead but more than anything else your daughter needs your grace and strength, not your grief.

Your daughter is fortunate to have been diagnosed at such a tender age. Please be aware our children get better; many recover completely given the proper treatments and therapies (and by recover I mean they are indistinguishable from neurotypical children). The earlier interventions are started the better.

The fact our children get better is extremely important in how you perceive the problem and how you proceed to help. Recovery is not a rumor, or a myth, or a dream, or an article of faith, it is a fact borne of tens of thousands of children who have improved dramatically, many recovered.

The idea of recovering children from autism is so far removed from people's concepts it is rarely thought about or acted upon. Currently the language of autism revolves around noise words like "Not Otherwise Specified" and "Pervasive Development Disorder" which reveal more about the meaning makers than the disease.

Linguist Benjamin Lee Whorf contended that language determines the nature and content of our thought. Absent a vocabulary, the vehicle of thought which carry the ideas of recovery forward it will not happen. The vocabulary of autism needs to be placed firmly in the best tradition of the scientific method; testing, empirical evidence, measurement, examination, and objectivity.

Hope is real. Autism is multivariate in presentation and cure. The disease bows to the collective weight of doctors working with therapists working with educators working with researchers working with parents working to recover their children. Your daughter's team of therapists, doctors, and educators must understand your goal and work together to implement your ideas and plans.

Therapy

You mention your daughter is receiving developmental and speech therapy at home. At her age <u>Applied Behavior Analysis</u> (ABA) is generally the most effective developmental therapy. You may want to include <u>sensory integration</u>. Other therapies to investigate for possible inclusion at a later date or to incorporate at the present depending upon her progress are <u>Verbal Behavior</u> (VB) and <u>Floortime</u> (DIR/Floortime).

Preschool You also mention your daughter's enrollment in a "neurohealth" preschool. While it sounds good there are a number of factors to be considered.

How many hours per week does she attend? She should be receiving a combined 30 to 40 hours a week (in-house and preschool) of one-on-one therapy. Does she have an <u>Individualized Education Program</u> (IEP)? Working in conjunction with the preschool you should develop an IEP with goals and objectives targeting skill-sets and behaviors. Do you receive a daily written log of her activities and behavior? A log, not a summary, detailing her day is a wonderful tool to track performance, uncover potential problems, and plan proactively. It also serves as a means for you to communicate in writing with the teachers. (I discuss this in more detail below.)

How eXperienced are the teachers/therapists working with your daughter? She needs bright, energetic individuals with a minimum of 1 to 2 years working with children with autism. It would be preferable if they have obtained or are working toward their master's degree. A supervisor with a minimum of 5 years experience should work closely with your daughter's team of teachers and therapists overseeing, coordinating efforts, and adjusting the program as necessary. Coordinate the efforts of home therapy with school therapy.

Act Now - Five Steps You Should Begin Immediately

1.) Find a doctor for your daughter who has recovered children with autism. Time after time parents fall into the trap of feeling a need to "educate" their practitioner. It becomes a full-time job, an end in itself. Left untreated autism is a deteriorating disease. Do not waste time playing "teacher." Your current doctor can be used to order tests while you locate a more qualified physician.

Your daughter's doctors do not have to be located in the same city or even the same state. Technology has created a global village. She can be videotaped so the doctor may better appreciate her behaviors and condition. Online video conferencing is also becoming popular. Conference calls, emails, instant messaging, and faxes facilitate real-time communication.

Work with a variety of professionals including allopathic, naturopathic, chiropractic, Ayurvedic, homeopathic and Traditional Chinese Medicine practitioners. For instance, children with autism should not take most over-the-counter medicines. Instead homeopathic remedies can be safely used to treat all the cuts, scraps, coughs, insect bites and other minor maladies our children are susceptible to. Ayurvedic and Traditional Chinese Medicine botanicals are marvelous for treating fevers, yeast, and parasites. Many chiropractors are trained in cranial sacral therapy, a form of manipulation which has been very helpful for many children with autism.

Defeat Autism Now! or DAN! practitioners are <u>listed here</u>. By and large DAN! practitioners follow the DAN! protocol for treating autism. The protocol is <u>available here</u>.

<u>Yahoo autism groups</u> are another excellent resource. Currently there are over a thousand Yahoo groups devoted to autism. They range in membership from a few dozen to several thousand. Join a number of the larger groups and post asking members for help in finding a practitioner.

Most of the members are fellow parents. The gold standard in the autism community is word-of-mouth recommendation by another parent. Parents will be honest and forthright with you about their experiences with physicians.

While we are on the subject of Yahoo groups they perform another invaluable service. You can post almost any question and some parent or group of parents will have answers, good answers, usually within 24 hours. The collective knowledge in the autism online networked community is without precedent. It is the promise of the Internet realized.

2.) Test for yeast and bacteria overgrowth in your daughter's gut. A form of yeast called candida albicans and other intestinal microbes are a known problem in children with autism. The Organic Acid Test (OAT) will help you determine the severity of the problem.

Typically children with autism have a history of ear infections which were treated with antibiotics. Antibiotics kill the "good" gut bacteria which normally keeps the yeast in check. Once the delicate balance has been disrupted yeast flourishes. Some of the behaviors linked to yeast overgrowth include confusion, hyperactivity, short attention span, lethargy, irritability, and aggression.

Attempting to restore intestinal balance is a constant struggle. Probiotics (meaning good bacteria) are an excellent supplement to begin replenishing the stock of natural flora. Controlling yeast may be accomplished using an anti-fungal medication like Nystatin in combination with natural yeast-fighting supplements like garlic, MCT oil (medium chain triglycerides) and activated charcoal.

Be careful. Other antifungal medications, like Diflucan and Nizoral inhibit the synthesis of steroid hormones. Treatment with either should not exceed 3 to 4 weeks followed by a 3 to 4 week rest period before beginning another round.

During yeast die-off symptoms and behaviors often temporarily worsen due to toxins flooding the body. Yeast die-off reactions generally begin within a week after antifungal treatments are started and last for 2 to 7 days, sometimes longer. Your daughter should drink plenty of distilled water, at least 8 ounces every 2 hours, during the die-off period.

There is growing evidence to suggest that individuals who experience greater than normal yeast die-off reactions suffer from elevated heavy metal levels. In addition, yeast overgrowth may only be eliminated in the long-term by removing the heavy-metal burden from the body. (Heavy-metal toxicity is something I will discuss in more detail below.)

3.) Implement a gluten- and casein-free (GFCF) diet. Almost 70 percent of children with autism respond favorably. The diet is not as difficult as it may seem at first. Download Mary Romaniec's presentation "GFCF and Do We Really Have to do this Diet" <u>from this page</u> which provides easy to follow, step-by-step instructions.

Instead of "GFCF diet" the phrase "GFCF environment" might be more appropriate. Gluten is found in toothpaste, hair shampoo, Play Dough, glue, and finger paint among other items. Gluten is also hidden in many foods you would never suspect, for instance, raisins are often dusted with flour (gluten) to keep them from clumping.

To effectively implement a GFCF diet a child's exposure to gluten and casein must be completely restricted (GFCF environment). Contamination can occur by touch, taste, or smell (skin, mouth, or nose). Some children are so sensitive they will react to gluten-free labeled foods which have been cross contaminated by the tiny amounts of airborne gluten found in plants processing other foods.

Call the manufacturers to ensure foods are gluten and casein free. Your daughter may not react to cross-contaminated foods. On the other hand be alert to the possibility. In addition, manufacturers often change ingredients and manufacturing operations. Food from a trusted company may suddenly become a problem. It is a good habit to constantly check food labels and keep in phone contact with companies.

The first month or two is a learning experience. Within a very short period of time, however, it will become second nature. Don't forget to throw away the old toothbrush when you begin the GFCF diet and begin using GFCF toothpaste.

In addition to the GFCF diet is the Specific Carbohydrate Diet (SCD). Many children who do not respond to the GFCF diet fare wonderfully on the SCD. Elaine Gottschall created the SCD and her book <u>Breaking the Vicious Cycle</u> is a testament that good science and clear, concise writing are not mutually exclusive.

Reading Elaine's book is to know the illuminating power of science in the hands of a gifted writer. Ideas are presented not only in terms of what to do, but more importantly in terms of why. Elaine's work is a program for action steeped in something lived (Elaine saved her own daughter using a special diet).

In conjunction with a special diet (GFCF or SCD) consider enzymes as part of your daughter's supplements. Enzymes will help her properly digest gluten and casein introduced inadvertently. Enzymes will also help her digest other proteins, fats, starches, carbohydrates, and fibers.

4.) Test for nutritional deficiencies. I'm happy your daughter responded well to the omega 3-6-9 fatty acids as well as the iron and vitamin supplement. Frustration is a behavior often associated with a deficiency in omega fatty acids. Care, however, must be exercised.

Children with autism face unique nutritional requirements and can be particularly sensitive to the introduction of supplements. For example, omega fatty acids can have the effect of increasing sound sensitivities, tantrums, and meltdowns. B6 needs to be supplemented with magnesium. Copper and zinc ratios are usually out of balance requiring additional zinc. Iron will exasperate constipation. Binders, diluents, lubricants, artificial flavorings, and colorings found in most vitamins can cause problems.

Our children are severely deficient in vitamins, minerals, enzymes, other nutrients, and fiber. A good place to start is to perform a nutritional assay. Please keep in mind each child is unique. How your daughter reacts can only be determined by carefully adding, or in some cases withdrawing, supplements and monitoring her behaviors, skin, nails, hair, stools, and urine. For the first year additional testing should be done about every 2 to 3 months to determine if she is digesting and absorbing the nutrients, and to make any necessary changes in supplements and dosage.

Vitamin Diagnostics is a good lab for testing for deficiencies in vitamins, minerals, essential fatty acids, amino acids, and neurotransmitters as well as testing for heavy metals and other problems associated with autism. Vitamin Diagnostics can be reached by phone at 1.800.886.7773 or by email at vitamindiag@optonline.net. Other good labs include <u>Doctor's Data</u>, <u>Immunosciences</u> and <u>Great Smokies</u>.

5.) Test for heavy-metals. Over the past few years it has become more and more evident many of our children suffer from heavy-metal toxicity, particularly mercury.

Mercury is in the air, water, food supply, dental amalgams (silver fillings), and it remains in many vaccines and the flu shot. It is not simply a matter of how much mercury our children are currently exposed to. Of great importance is the mother's exposure before, during pregnancy, and while breastfeeding. Studies by the CDC indicate that nearly 8 percent of childbearing-age American women currently have blood levels of mercury that exceed safe amounts.

Many women received Rhogam shots during pregnancy and immediately after delivery. Rhogam, until recently, contained as much as 25 mcg of mercury. The mercury in a mother is passed to the developing fetus or nursing infant. Other sources, for example, in <u>consumer products and fish</u> can increase the level of mercury to the toxic tipping point.

We normally excrete mercury through our hair, urine, feces, nails, and breath. Many children with autism, on the other hand, cannot effectively eliminate mercury. Their detoxification pathways are broken with mercury in the environment continually adding to burden.

<u>A hair-sample study by Amy Holmes, MD</u> found strikingly lower levels of mercury in the hair of children with autism than neurotypical children. Dr. Holmes collected samples of baby hair, the first haircut, of 43 boys with autism and 14 neurotypical boys.

The hair level of mercury in the boys with autism was barely detectable. The findings suggest children with autism cannot excrete mercury from their systems. The mercury builds to toxic levels. More information about Dr. Holmes treatment for mercury is <u>available here</u>.

<u>A study by Jeff Bradstreet, MD et al. c</u>orroborates Dr. Holmes' conclusion that children with autism lack the ability to eliminate mercury. The study evaluated the concentration of mercury in the urine following a three-day treatment with DMSA. DMSA (meso2,3 dimercaptosuccinic acid) is a chelating agent which binds with and pulls heavy metals out of the body. The test results showed mercury in the urine of children with autism to be six times higher than the control group.

Contrary to claims by vaccine manufacturers touting "mercury free" vaccines an investigation by Health Advocacy in the Public Interest (HAPI) recently found mercury in all four vials tested. This despite manufacturer claims that two of the vials were completely mercury free. Boyd Haley, PhD, Chemistry Department Chair, University of Kentucky, feels that if mercury can be detected in any vaccine using standard instrumentation, the content should be disclosed in the product insert and manufacturers should not be allowed to call the product "mercury free."

Heavy metal testing can be done using a sample of hair (2 - 3 cm) cut from the nape of your daughter's neck and sent to Vitamin Diagnostics or one of the other laboratories mentioned above. You will need to check with each lab for their policy about ordering test kits. Some require a physician's signature.

Hair tests while a good general indicator of heavy metals do not provide absolute certainty. There is a small subset of children with autism who excrete far more mercury than average. Another test called a challenge test involves the use of a chelating agent followed by collecting and testing the urine for heavy metals. The challenge typically involves multiple doses over a 3-day period. Often multiple challenges are necessary before a child begins to eliminate the mercury in their system.

Many parents are currently using DMSA as the chelating agent. Although DMSA is approved by the FDA Dr. Boyd Haley considers DMSA to be a neurotoxin. Dr. Rashid Buttar is experiencing great success using transdermal (applied to the skin) DMPS (2,3 dimercaptopropane sulfonate) as the chelating agent. A presentation by Dr. Buttar is available on this page.

Education

Socrates when asked what is good replied "knowledge." There is no greater good you can do for your daughter than becoming knowledgeable about all aspects of autism. You are the expert. You know her abilities, desires, passions, problems, obstacles, and potential as no one else ever will or could.

A number of good books to read include Children With Starving Brains, Biological Treatments for Autism and PDD and Let Me Hear Your Voice. Autism is a dynamic field. Try to keep abreast of the latest developments. The Schafer Autism Report is a free daily e-newsletter which provides important and timely information about autism. Also, the Yahoo groups previously mentioned will help.

Responsibility

Several years ago my son started ABA therapy. Crying during the initial ABA sessions, although common, is nonetheless heart-wrenching. This particular session Jarad's cries seemed different. The therapist was physically attempting to keep Jarad in his seat, forcing him to sit. I agonized for ten minutes trying to decide if I was imagining things. Finally, I entered the room picking Jarad up to comfort him, much to the chagrin of the therapist. I could see the wheels turning in her head, "overly-protective parent rushes to aid of child, disrupting session, thwarting progress."

Jarad's bottom and back of his legs were dotted with punctures. Being forced to sit compressed the cushion pushing the sharp screws into Jarad. The tips were not visible, hidden by the plastic seat cover. Jarad's screams were cries of pain, not frustration.

Trust your instincts. No matter the time, place, or professional involved if you feel the least bit uncomfortable remove your child from the situation. Give yourself time to reflect, collect your thoughts, weigh other options, and make an informed decision. You are the final and ultimate authority on what is best for your daughter. Do not be bullied.

For some it is a terrifying thought, the idea of assuming complete responsibility, the equivalent of stepping off the edge of a cliff at night. It can be the greatest difficulty parents face on the road to helping their children - the transition from trusting to questioning from acquiescence to Cartesian doubt.

Question everything. The personnel at your daughter's preschool may be well-intentioned and wonderful professionals. As harsh as this may sound they are not your friends. Cultivate clinical detachment when dealing with professionals. Attempt to put as many decisions as possible in writing. A daily log can serve as an important permanent record for communication between you and the school. Sections can be devoted to requests, decisions, daily activities, special requirements, nutritional supplements, dietary restrictions, and other categories.

Experimenting is Good

While experiment has a Frankenstein-ish connotation it is the bedrock of science. Many parents, unfortunately, distance themselves from the idea.

You will need to experiment with your daughter. For example, she may have great difficulty with any number of nutrients. Regardless of test results indicating particular deficiencies it is often not as simple as adding them to the mix.

Proceed cautiously. Should there be a problem experiment with the dosage, experiment with the time of day a nutrient is given, experiment with every other day or every third day dosing. Your daughter's unique constitution is the only barometer of a treatment's efficacy.

I am not aware of any treatment that does not cause some percentage, no matter how small, of regression in children with autism. Regression is generally not permanent and reverses when the offending treatment is discontinued.

Develop a Plan

Develop a 3-, 6-, and 12-month biomedical plan similar to an IEP. For instance, your daughter's IEP will contain specific goals like identifying shapes along with the methods employed to reach the goal. The same type of goal-driven plan may be employed for biomedical treatments.

Consider the results of a hypothetical organic acid test indicating your daughter suffers from yeast. The goal is to drastically reduce the amount of yeast in your daughter's intestine. Define quantitative measures (numbers or percentages) to use as milestones (goals to reach in 3, 6 and 12 months).

Again hypothetically consider her yeast "score" is 100. Normal is 5. The 3-month goal could be 60, the 6-month goal 20 and the 12-month goal 8. What methods will be utilized to reach the goals? MCT oil, Nystatin, probiotics and garlic are all effective in fighting yeast. She may have a bad reaction to one. Should another supplement be substituted? Which one? There are at least a dozen others. What dosage? What are the side effects? What if in 6 months the level of yeast is elevated?

Perform the exercise for every problem (e.g., sound sensitivity, short attention span) or deficiency (e.g. vitamins) you can identify paying particular attention to the holistic action among treatments. For instance, omega-6 may cause sensitivity to sound. After removing the omega-6 your daughter could begin audio integration therapy and the omega-6 reintroduced.

Developing a plan uncovers scenarios and leads to a better and deeper understanding of options and constraints. The plan is not static and is best if it accurately reflects your daughter's current condition as well as the latest treatment options.

Keep a Log

It is very easy to forget when a supplement was added or when a behavior first appeared. You have enough on your mind without trying to remember which came first. Also the act of writing serves as an aid to memory.

Vaccinated versus Non-vaccinated

I am not aware of any credible studies which compare the rates of autism in vaccinated versus non-vaccinated populations. There have been some studies which after initially receiving much attention by the mainstream media were shown to be fatally flawed, for instance, the "Danish" studies.

You may be interested in the Geier's research which found children are 27 times more likely to develop autism after exposure to three thimerosal-containing vaccines than those who receive thimerosal-free versions. Mark Geier, MD, PhD, and his son David, are the only self-funded researchers publishing in peer-reviewed journals on thimerosal and autism using CDC data.

A piece of great news and another indicator of the effect of mercury-containing vaccines versus mercury-free vaccines is the recent drop in the number of cases of autism reported in California. For the first time in the 35-year history of collecting data in July, 2004 California reported a third consecutive quarter drop in the number of children with autism. The decrease in the number of children with autism is the result of the reduction of thimerosal in vaccines beginning in 2000 and 2001.

Much more work remains to be done as the autism community moves forward both at the state and federal levels to eliminate a known neurotoxin from vaccines and full shots. This year Iowa became the first state to ban the use of thimerosal in childhood vaccines with many other states preparing to introduce similar legislation. At the federal level Congressman Dave Weldon, MD, and Congresswoman Carolyn Maloney introduced legislation - HR4169 - for a broader ban on the use of mercury in vaccines.

Can you offer a better understanding of orthodox medicine as it applies to autism treatment?

I find it helpful when attempting to understand a field, orthodox medicine in this case, to put it in terms of familiar ideas. My background is software engineering. Surprisingly, at a fundamental level software engineering has more in common with medicine than it does with many of its engineering cousins, like mechanical and aerospace engineering.

Software engineering and orthodox medicine suffer from the same underlying problem. The problem which causes your Windows Operating System to crash is the same problem which prevents orthodox medicine from helping children with autism.

Two types of systems: continuous and discrete

The distinction between software engineering and medicine, on the one hand, and mechanical and aerospace engineering on the other has to do with two different types of systems: discrete verses continuous. Software programs that run on your PC, like Windows, are discrete systems. Aerospace, mechanical and other engineering disciplines work largely in continuous systems.

Continuous systems

Here is an example of a continuous system. If I throw a ball into the air I can expect the ball to reach a certain height and return. It would be astonishing if the ball stopped in midair and then began accelerating upward.

In continuous systems, like throwing a ball in the air, certain laws apply. As a result continuous systems can be modeled in mathematics. In continuous systems small changes in input result in small changes in output.

Variables in continuous systems are knowable and predictable. Continuous functions are used to accurately map inputs to outputs. There are no hidden surprises.

Continuous systems also exhibit a separation of concerns. In large complex continuous systems, such as an airplane, systems which are not connected will not impact one another. For example, we would be very unhappy if, as a result of a passenger in seat 38E turning on an overhead light, the plane immediately executed a sharp dive.

Discrete systems

Discrete systems (software) are not constrained by the same limitations as continuous ones. In software small changes in input can result in drastic changes in output, for instance, click the print icon in Windows and your system crashes.

The values of variables in discrete systems are not always predictable. A variable may be 5 and after the next instruction is executed it may be 20 or 900. The value cannot always be predicted until the program runs. Discrete systems are non-deterministic.

In discrete systems any part of a system can potentially affect any other part of the system. In other words, discrete systems do not benefit from naturally occurring separation of concerns. Every component in discrete systems is potentially connected to every other component. In discrete systems the ball could easily continue accelerating upward and the plane could execute a shape dive.

Continuous systems (throwing a ball, cars, bridges) characteristics

- Small changes in input produce correspondingly small changes in output.
- Outputs can be accurately predicted based on inputs.

• There is a separation of concerns. Every element is not interconnected (a plane's fuel system is not connected to its landing gear).

• The laws of physics apply, there are no hidden surprises (can be modeled by continuous functions).

Discrete systems (software) characteristics

- Small changes in inputs can produce drastic changes in outputs.
- Outputs cannot always be predicted based on inputs.
- There is no naturally occurring separation of concerns. Every element in the system is potentially influenced by every other element.
- The laws of physics do not apply (cannot be modeled by continuous functions).

The problem domain

Grady Booch states, "Since we have neither the mathematical tools nor the intellectual capacity to model the complete behavior of large discrete systems, we must be content with acceptable levels of confidence regarding their correctness."

It's chilling, but accurate: We have neither the mathematical tools nor the intellectual capacity to model the complete behavior of large discrete systems. Moreover, large discrete software systems pale in comparison to the complexity of the human body.

A misdiagnosis

Orthodox medical theory and practice misdiagnoses discrete systems as continuous. The belief that children with autism function as continuous systems has been devastating in terms of diagnosis, research, and treatment. While orthodox medicine does not use the term continuous systems its diagnostic techniques, organization, and treatment options operate under many of the same assumptions.

Orthodox medicine is obsessed with germ theory and disease states. The emphasis is on outputs and algorithms, or to put it in medical terms, on diseases (symptoms) and formulistic treatments. Only at a very superficial level does orthodox medicine permit the possibility of discrete systems behavior (any input has unforeseen outputs, small inputs produce drastic outputs).

The differences between continuous and discrete systems demand different mindsets, new kinds of analysis and synthesis, and a different world-view. The most important step is to acknowledge the problem domain, to grant, rather than deny, the types of characteristics exhibited by children with autism are the same as those found in discrete systems.

Small changes in input and predictable outputs

Esteemed biochemist Roger Williams, PhD, found a 200-fold difference in calcium requirements among different healthy human subjects. Recent research in the toxicity of mercury has revealed sensitivities to mercury vary as much as a million-fold from one individual to another.

Dr. Williams stressed that inborn differences between humans are extensive, significant, and crucial to understanding and solving most human problems. Dr. Williams also found nutritional status can influence the expression of genetic characteristics. The most important consideration according to Dr. Williams is biochemical individuality.

Vitamins and other nutritional substances may well be the greatest and most enduring of medical discoveries of the 20th century. Vitamin A (1912, the first vitamin to be discovered) was named retinol because, without it, a healthy retina in the eye could not be formed. With the B-vitamins came the cures for beriberi, pellagra, pernicious anemia, nerve degeneration, enlarged heart, energy production, and many others diseases and conditions. Incredibly, orthodox medical practitioners are not required to understand nutrition to be licensed to practice medicine.

The biochemistry of children with autism reveal many nutritional deficiencies, including vitamins, minerals, essential fatty acids, and amino acids (small inputs). Many children given supplements improve along a number of axes (profound

outputs).

For instance, children with autism often rub and poke their eyes. Some must be restrained with head gear to keep from gouging their eyes. It's due to a calcium deficiency. The red rash seen around the lips, often called clown lips, is due to a vitamin B2 deficiency.

Viewing a child with autism in terms of discrete systems behavior provides a more accurate model than the current continuous systems concepts. Children from autism suffer from extreme chemical sensitivities, food allergies, delayed food allergies, hypersensitivity to sound and light (small inputs). In addition, how different children react to trace amounts of the same substances cannot be predicted (outputs – biochemical individuality). One child may suffer anger, another constipation, a third diarrhea.

Limited by continuous systems thinking orthodox medical practitioners cling to the notion that your child is the same as my child is the same as every child. Autism is a one size fits all label precluding the necessity of further individualized investigation.

Separation of concerns

Orthodox medicine is a house defined by separation of concerns. The two general divisions are medicine and surgery. Within medicine there is internal medicine, cardiology, gastroenterology, pediatrics, geriatrics, dermatology, immunology, epidemiology, allergy, neurology, psychiatry, radiology, and pathology. Surgery is divided into surgery, orthopedics, urology, ear, nose and throat, obstetrics and gynecology, anesthesiology, and ophthalmology. Anatomical divisions include cardiovascular, nervous, immune, reproductive, gastrointestinal, urinary, integumentary, musculoskeletal, endocrine, reticuloendothelial and hematologic systems.

One technique of mastering complexity has been known since ancient times: Divide et impera (Divide and rule). Granted, many important discoveries are due to analytical techniques which by partitioning (separating) produce manageable areas of study. Partitioning, however, is not without its own effects and not all of them are good. Analysis is only part of the equation.

The separation of orthodox medicine into its current specialty and anatomical divisions is not by necessity, but by convention. Divisions evolved arbitrarily over a period dating to the middle ages. Today, it stands as the defining organizational paradigm of orthodox medicine.

The blood brain barrier (BBB) was and is touted as a natural partition separating the brain from the body protecting our most vital organ from all manner of potential toxins. Recently, however, a number of methods have been discovered allowing toxins to penetrate the barrier. The entire blood-brain barrier edifice was built on experiments conducted in the 1920s and 30s.

It was widely held, practiced, and believed that emotions originate in the brain. The hypothalamus was considered the seat of emotions which trickled down through its neural connections to the back of the brain, or brainstem, or through the secretions of the pituitary gland to the body. It is now understood emotions can originate in the body as well the mind, the paths are two-way, not one-way streets.

Only within the past twenty years have cellular communication capabilities been discovered with the detection of interleukins, now called cytokines. The list of discoveries is endless, as it should be. Yet experience, not just theory must guide our understanding. There is an old adage, "When theory meets reality, reality always wins."

A child with autism symptoms appear to originate in the mind, but that is only to the untrained eye which avoids looking at the entire body. Every input (possibility), including food, toxins, yeast, and others must be considered when a child bangs their head on the ground and walks on their toes. In children with autism the ball will continue upward and the plane will execute a sharp dive.

Sidney Baker, MD, one of the founders of DAN! says "Anatomically the CNS (central nervous system) and immune systems are quite distinct and different. One is made up of stationary long branching permanent cells with a compact headquarters between ones ears. The other is made up of a disseminated population of short-lived mobile cells with no specific organ to call home. Pick up any textbook of anatomy, physiology, or pathology. The CNS and immune system chapters are widely separated as are the experts who wrote the chapters. From the way I see it, however, they are a functional unit."

Dr. Baker suggests a different world-view, a separation of concerns based not on anatomy, but on functionality, a more natural and richer model. Functional medicine is part of a larger holistic health care movement which seeks to integrate, not separate. Holistic practitioners follow in the footsteps of empiricist physicians in the continuing battle for medicine dating to the dawn of science.

Empirics promote the practice of medicine based on observation and experience. Rationalists (today known as orthodox

medicine) seek medical certainty in formal logic (mathematics). Formal logic, however, has proven to be inadequate as a means to model large **discrete systems**.

Organizational behavior

Organizational behavior theory can be used to help understand, to examine how organizations work. The survival instinct is well established as one of the basic foundations in life, but it is not just life forms which exhibit survival strategies, organizations do so as well. Sterling's pioneering work discovered a key organizational foundation: An organization's chief concern is the optimum allocation of its resources to ensure its own survival.

The specialties and anatomical divisions in orthodox medicine are organizations that act in their own best interests regardless of stated goals. Organizational behavior also finds the structure of an organization dictates its solutions, not to change them, but to reflect them.

The super-structure surrounding orthodox medicine, including fundraising, allocation of resources for research, prestige, power, reimbursement for medical care and medical education depend on the current organizational format. Internal as well as external forces dictate its continuance.

As a biomedical disease autism does not fit well into the current separation of concerns. (Autism is a multisystem disease with neurological, gastrointestinal, endocrine, immune, developmental, and communicative abnormalities.) Turf warfare, politics, bureaucratic inertia, hubris, and other "human" factors prevent orthodox medicine from applying an interdisciplinary approach to autism.

Attempting to "divide and rule" the body orthodox medicine has created walls to understanding. Orthodox medicine places a premium on analysis yet lacks an equal emphasis on synthesis. The organizational structure of orthodox medicine is an artificial separation of concerns. The tool has usurped reality as a world-view. Derivations from the model, like autism, are not addressed.

Problems with orthodox medicine

Do not equate orthodox medicine with medical science. Orthodox medicine is deeply flawed; its science preserved in amber-logic, existing outside of experience. Orthodox medicine has metastasized; rigidly staying within the confines of its own self-reinforcing coterie making it singularly unable to adjust, to learn, to help.

Orthodox medicine's fetish with continuous systems thinking, specialties and anatomical divisions relegates children with autism to a number of pre-determined, hugely unqualified, sub-specialists, among them pediatric neurologists and behavioral psychiatrists, where they are largely declared beyond the help of "medical science."

To any of the countless questions parents raise when talking to orthodox medical practitioners the answers are uniquely uninformed, misleading, and often dangerous: Environmental toxins? Not a problem: Chemical sensitivities? Unlikely: Food allergies? Unproven: Vaccines? Completely safe: Increase in autism? A theory: Nutritional supplements? Baseless: Cause? Genetics: Treatment? Psychotropic drugs: The future? Consider institutionalizing.

At its core orthodox medicine is antithetical to autism. A rigid reliance on deterministic disease definitions spins jabberwocky non-answers inducing Alice in Wonderland effects. After reading Jabberwocky Alice proclaimed, "Somehow it seems to fill my head with ideas - only I don't know exactly what they are."

Summing up

All children with autism exhibit discrete systems behavior (widely divergent outputs are exhibited based on similar inputs). Key for parents is recognizing the biochemical individuality of each child, bringing biomedical treatments to bear at the most appropriate points.

Much as a jeweler carefully giving a gentle tap on a diamond reveals its inner symmetry, sparkle, brilliance and fire parents can bring the inner beauty of their children to the world by biomedical "tapping" at the "right" points. Our children are diamonds; each is unique, infinitely more precious.

Contrary to the widely held orthodox medical opinion, our children get better; many fully recover (please see my previous column). Following Alice down the rabbit hole will never reveal the inner brilliance and happiness of our children, addressing their biochemical individuality and needs will.

For more information please visit <u>http://www.autismone.org</u>

Do You Suspect Autism in a Grandchild, Niece, Nephew, Neighbor, Etc?

Telling a parent that you suspect their child has autism can be a scary process. Yet, it's best for the child to not wait. Here are some tips that may help.

1. **Make Sure** – Autism is a combination of serious symptoms. Be sure you are fully aware of the symptoms and have observed the child enough to know if the symptoms are present. Educate yourself thoroughly before causing false panic.

2. **Gather the Literature** – Whether you get it from a reliable book, accredited web site, or other proven source, make sure you have gathered literature that outlines the signs of autism, how it is diagnosed, and where to find help. It may be helpful to mark the signs you see in the child on the literature itself. Be sure to make two copies if it is a two-parent home, and have an extra copy on-hand for yourself. Also, make sure the literature is simple and easy-to-read, and store it in a bag or briefcase until you meet with the parents.

3. **Call** – Let the parents know you would like to sit down and speak with them. If they ask what it's about, you can explain you are conflicted about something and would like to get their feedback. That way, you're not lying, but at the same time, you aren't blurting out "There may be something wrong with your child."

4. **Don't Wait** – Absolutely <u>do not hold off</u> telling them because you fear they'll be mad at you. It's easy to get caught up in not wanting to upset them too much or make them angry, but *don't*. Their reaction will likely be less than favorable. Remember, you're doing this for the child. The sooner you tell them, the better.

5. **Do Not Tell One Parent** – If it is a two-parent home, make sure both parents are present when you voice your concerns. Call before you leave for the meeting to confirm both parents will be there. If one is unable to attend, ask to come at a time when both may be present.

6. **Explain Your Reasoning** – Once you have sat down with the parents, explain you are there out of caring for them and their child. Speak about your observations. Because early intervention is so important, be sure they understand that, although you're sorry to bring this concern to their attention, you feel as though you are doing the right thing. If you've had any hands-on experience with autistic children, be sure to remind them of this.

7. **Present the Literature** - Once you've explained your intentions, allow them to look at the literature you've prepared without interruption. The pages that outline the symptoms should be the first thing they see.

8. **Don't Be a Know-It-All** - Do not overwhelm them with statistics, facts, or your vast knowledge of autism. In fact, once they review the literature, encourage them to get an opinion other than yours. Be sure you portray yourself as a messenger of information more than an authority on the subject. Chances are, if the child's doctor hasn't picked up on anything, they will automatically consider you wrong in your assessment. Ask them to please take the information to the doctor and request a referral to an early intervention center. Help them to understand in a delicate way that it will not hurt the child to be evaluated and may only be a precautionary measure. The less you push, the more receptive they will be.

9. **Do Not Argue Back** – In the event that one or both parents becomes angry with you and wants to "shoot the messenger," or even attempts to argue the points you've presented, be sure to remain calm and compassionate. Do not argue. If it becomes too tense, leave the literature with them in a very kind way and follow-up later. There's also a chance you will be asked to leave, or that one parent will leave the discussion. Do not argue...do not follow the parent who has left. Simply leave the literature and be on your way.

10. **Understand** - Go into the situation understanding that everyone handles devastating news differently. Do not assume you will receive a 'thank you' or be looked at as a hero. You most likely will not. Parents do not want to hear their child is sick. *Having* to know in order to fix the problem is much different than *wanting* to know. Don't assume you're doing them a favor even though you're technically an angel in disguise. In time, they will thank you, but for now they will feel the way they feel and react accordingly. Accept and understand. 11. **Offer Support** – Chances are you are also devastated. If it is your grandchild or other family member who may have autism, you may need time for yourself to cope and grieve. During the meeting, be sure to focus on their sorrow and not your own. They are hearing the news for the first time, and their lives have just been turned upside-down. They need support now more than ever. If they are angry at you, choose to be strong for them by offering support. By doing this, you are quickening the healing process as well as helping the child.

12. **Give It Time** – Do not call an hour later asking if they're okay. Wait a day or two to call as a gesture of support. Do not make the conversation about their reaction, or your reaction to their reaction. Simply offer support. If they do not wish to speak with, don't take it personally. Remember, they're grieving for their child and, in some cases, are still trying to grapple what they've heard. Make sure to communicate with them on their terms and not your own.