

Advocating for Medical Treatment, When Practitioners See Autism as “Behavioral”

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Disclaimer

- Information provided here is for educational purposes only
- Not to be taken as specific medical advice
- All medical decisions regarding your child’s health issues should be discussed with your health care provider

Collaborative Model



Goals for today:

1. Review the various specialists that may be involved in your child's care.
2. Give you, the parent, tools/resources to share with other disciplines that will maximize your child's treatment.
3. Define the various medical specialists.
4. Discuss ways to share your story so the providers will not simply see behaviors.
5. Give you resources to develop a treatment plan that fits your child's medical needs.

What Biomedical Doctors Do

Biomedical Model

- They listen to my concerns and don't blow me off.
- I feel like they can help my child become healthier.
- I don't want to just be using medication to treat my child's symptoms.
- I have heard from other parents some kids actually can recover.
- Individual/patient based
- Looking at symptoms
- Objective physical and chemical findings
- Biochemical, metabolic and gastrointestinal abnormalities
- Unifying framework
 - Research-based treatment options
 - Treatment is individualized

Biomedical Doctors Are Not to Be the Sole Medical Provider

- Their training is not in primary care and referral to specialists.
 - The biomedical practitioner often does not set up their practice to be available in an urgent care situation. In addition, evaluation of that child in medical situations may require a physical exam.
 - Hours of operation: if emergency issues arise, your child will need to be evaluated by a physician available to you. It is better to have established this relationship before the emergency.
- Prescriptions for coverage of behavioral therapy, OT, and PT require diagnosis that biomedical providers often do not use.
- Out-of-network status affects insurance coverage and may cause an unnecessary increase in out-of-pocket expenses.

The Affordable Care Act

- The Affordable Care Act requires physicians or other eligible Non-Physician Practitioners (NPPs) to enroll in the Medicare Program to order/refer items or services for Medicare beneficiaries, including those physicians and other eligible NPPs who do not and will not send claims to a Medicare Contractor for the services they furnish.
- Effective May 1, 2013, CMS will turn on the edits...if the ordering / referring provider is identified on the claim, but is not enrolled in Medicare, the claim will not be paid.
- Often other insurances, including Medicaid, eventually follow Medicare's guidelines; parents will need to be aware of how changes will affect coverage for testing, labs, and prescriptions for therapies, because biomedical doctors typically opt out of Medicare.
- Centers for Medicare and Medicaid Services — www.cms.gov

Biomedical Practitioners

Reasons to Seek Biomedical Practitioners

- Desperation
- You as a parent believe there is something wrong
- They listen and understand
- Initial intake is thorough
- Treatment plan equals hope

Reasons to Seek Mainstream Providers

- Need more medical care
- Specialized testing and evaluation often can not be ordered by your biomedical practitioners
- Address specific medical need that your child presents with, such as low tone, diarrhea, etc.

Advocating for Medical Treatments

- When you are at the doctor's office, remember that the first three sentences out of your mouth dictate the rest of your office visit.
- "I am here because, *and state the medical issue*"
 - My child is having headaches
 - My child hasn't had a stool in four days
 - My child is not sleeping.
 - My child is staring, according to school personnel

Current Behaviors that Define the Medical Issue

Behaviors

- Doesn't Sleep
- Lays around all day
- Picky eater
- Stims
- Obsessive thoughts
- Squints his/hers eyes
- Dark circles under eyes
- Head bangs

Medical Terms

- Insomnia
- Low tone
- Diarrhea/constipation/pain
- Blinks eyes
- Obsessive Compulsive Disorder
- Seizures
- Allergies
- Headache

Parent Observations Supporting the Medical Concern

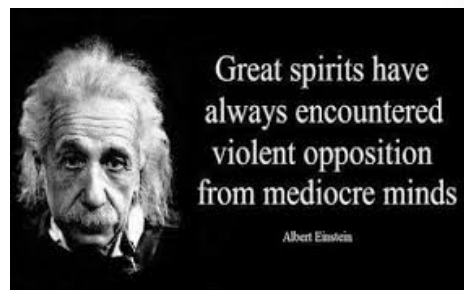
- My child is having headaches
 - Likes a dark room
 - Seeks counter pressure on head
- My child only stools once a week
 - My other child stools every day
- My child is staring, according to school personnel
 - Their thought is he may be having seizures

The Team

Cooperative Model



Uncooperative Model



Medical Providers You May Come in Contact With

- Pediatrician
- Neurologist
- Gastroenterologist
- Dentist
- Occupational/physical therapist
- Hospital staff
 - Emergency room
 - Surgery
 - Lab

Pediatrician

- According to the American Academy of Pediatrics:

AUTISM

- Autism spectrum disorders (ASDs) are a group of related developmental disabilities, caused by a problem with the brain, that affect a child's behavior, social, and communication skills.
- **There is currently no cure for ASDs**, however, children with an ASD can progress developmentally and learn new skills.
- The AAP strongly believes in the importance of early and continuous surveillance and screening for ASD to ensure that children are identified and receive access to **services** as soon as possible. The sooner an ASD is identified, the sooner an intervention program can start.
- Scientific understanding of the cause of autism is far from complete. The AAP strongly supports ongoing studies funded through the Centers for Disease Control and Prevention and the National Institutes of Health that are trying to **determine factors in our modern environment that may be responsible for autism.**

www2.aap.org/healthtopics/autism.cfm

Pediatrician

- Find a pediatrician that will listen and keep an open mind
- Research and find support for your decisions about vaccines
- <http://vaccinationcouncil.org>
- Ask other parents names of pediatricians or family doctors they like

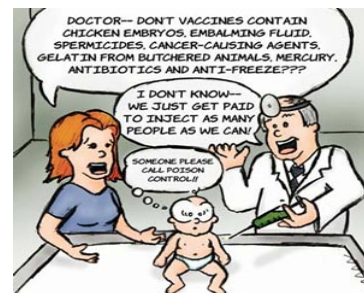
When Looking for Pediatrician or Specialist

- Your greatest resource is other parents like you
 - School parent groups
 - Parent support groups
 - Conferences
 - Yahoo groups
 - Facebook
 - Meetups

Lots of Families Don't Have a Pediatrician

- Parents often believe they do not need a primary care physician for their child with autism
- Parents want to avoid the question, "Is your child up to date on vaccines?"
- Providers have the belief that autism is behavioral, not medical
- Parents no longer trust mainstream medical providers; many believe their vaccine policy already harmed the child once
- Parents don't want to feel bullied or pressured to do anything and fear they will be forced to do something they don't want to

How about the vaccine question?



What Your Pediatrician Can Do for You

- Referrals to other providers
- Your support when emergency care is needed
- Current physical exam for anesthesia or other procedures
- Well check up
 - Monitor for change in height and weight
 - Place to document progress from biomedical treatment
- Documentation of current medical conditions that arise
 - Ear infection
 - Strep throat
 - Chronic diarrhea and/or constipation
 - Specialty providers report back to pediatrician to allow for continuum of care

How to Structure Your Annual Check Up Appointment

- When scheduling with the primary care doctor, explain to the scheduler you may need more time.
- Remember your list of concerns and bring them to your appointment.
- Share labs that were done by your biomedical practitioner through the hospital and standard lab.
- Explain what medical treatments have helped, and what physical change you have seen as a result of implementing the treatments.
- When explaining a diet or supplement you have your child on, keep in mind your audience and the familiarity with treatments.

Medical Model

Medical Condition

- Low Tone

Medical Treatment

- Physical Therapy
- Occupational Therapy
- Metabolic/Neurologic
- Mitochondrial
- Endocrine

- A biomedical practitioner may not be able refer your child to all these specialists.
- Your pediatrician can do this.
- The pediatrician will refer, but the parent presents the issue/concern.
- The pediatrician's role is to set priorities.

Neurologist

AAN Guideline Summary for CLINICIANS SCREENING AND DIAGNOSIS of Autism

This is a summary of the American Academy of Neurology (AAN) and Child Neurology Society (CNS) guideline on screening and diagnosis for autism. This practice parameter reviews the available empirical evidence and gives specific recommendations for the identification of children with autism.

This approach requires a dual process:

- 1) routine developmental surveillance and screening specifically for autism to be performed on all children to first identify those at risk for any type of atypical development, and to identify those specifically at risk for autism;
- 2) to diagnose and evaluate autism, to differentiate autism from other developmental disorders.

<http://www.aan.com/globals/axon/assets/2605.pdf>

http://www.ninds.nih.gov/disorders/autism/detail_autism.htm

- **How is autism treated?**
- There is no cure for ASDs. Therapies and behavioral interventions are designed to remedy specific symptoms and can bring about substantial improvement. The ideal treatment plan coordinates therapies and interventions that meet the specific needs of individual children. Most health care professionals agree that the earlier the intervention, the better.
- **Educational/behavioral interventions:** Therapists use highly structured and intensive skill-oriented training sessions to help children develop social and language skills, such as Applied Behavioral Analysis. Family counseling for the parents and siblings of children with an ASD often helps families cope with the particular challenges of living with a child with an ASD.
- **Medications:** Doctors may prescribe medications for treatment of specific autism-related symptoms, such as anxiety, depression, or obsessive-compulsive disorder. Antipsychotic medications are used to treat severe behavioral problems. Seizures can be treated with one or more anticonvulsant drugs. Medication used to treat people with attention deficit disorder can be used effectively to help decrease impulsivity and hyperactivity.
- **Other therapies:** There are a number of controversial therapies or interventions available, but few, if any, are supported by scientific studies. Parents should use caution before adopting any unproven treatments. Although dietary interventions have been helpful in some children, parents should be careful that their child's nutritional status is carefully followed.

Why See a Neurologist?

- Inconsistent acquisition of skills, loss of functioning
- Seizure activity
 - Tics
 - Twitch or move uncontrollably
 - Staring
 - Sudden outburst of aggression
 - Drool
 - Lose bladder control
 - Muscle spasms

Why See a Neurologist?

- The prevalence of epilepsy among ASD patients ranges from 11% to 39%, with a higher prevalence in patients with comorbid mental retardation and motor deficits.
- The onset of epilepsy in ASDs is biphasic in distribution, peaking before 5 years of age and again in adolescence.
- Selection of anticonvulsant medication and treatment duration in children with epilepsy and an ASD does not differ from routine childhood epilepsy treatment.

Myers SM, Johnson CP; American Academy of Pediatrics Council on Children with Disabilities. Management of children with autism spectrum disorders. *Pediatrics*. 2007;120:1162–1182.

Neurology to Gastroenterology

- Neurology is usually the first specialist a pediatrician will refer you to
- Gastrointestinal complaints are common but frequently go unaddressed
- The next area of specialty your child may need to see is the gastroenterologist

Puzzle Pieces Related to the Gastrointestinal Tract

- Food refusal
- Gagging
- Spitting
- Arching of the back
- Self pinching
- Eroded back teeth
- Toe walking
- Bloating stomach
- Daily BMs, yet stools are large or scanty
- Laying over objects to put pressure on the stomach
- Head banging
- Sour breath
- Frequent night waking
- History of colic
- Excessive chewing or biting of the arm

Gastrointestinal Abnormalities

- **Maldigestion**
 - Decreased activity of digestive enzymes (Horvath, 1999; Buie, 2004)
 - High levels of opioid peptides found in urine of autistics. (Reichelt, 1997)
 - IgG Food Sensitivities
- **Malabsorption**
 - Fat Soluble Vitamin Deficiencies
 - Essential Fatty Acid Deficiencies, Omega 3 Deficiencies
 - Essential Amino Acid Deficiencies
- **Dysbiosis**
 - Dysbiosis or altered bowel flora (Rossenau, 2004)
 - Clostridial overgrowth (Sandler, 2002, McFabe 2007)
 - Persistent measles virus (Wakefield, Krigsman)
- **Gut Inflammation**
 - Autistic Enterocolitis, Lymphoid Hyperplasia (Wakefield, 1998)
 - Increased intestinal permeability leading to food sensitivities and autoimmunity (Vodjani, 2002)
 - Increased pro-inflammatory cytokines – LP, TNF alpha, IFN gamma (Ashwood, 2004; Jyonuchi 2005)
 - Proinflammatory response to dietary proteins (Jyonuchi, 2004)
 - Proinflammation similar to Autistics found in immunized Monkeys (Hewitson, 2008)

Prepare Yourself to Get the GI Referral

- List current concerns
- Review the literature
- Know what you want and why
- TACA “Poop Page” at www.tacanow.org/family-resources/the-poop-page/
- Gastrointestinal Pathology in Autism: Description and Treatment www.medicalveritas.com/AKrigsman.pdf

Articles for Parents and the Gastroenterologist

- Gastrointestinal Pathology in Autism: Description and Treatment by Dr. Arthur Krigsman — written for parents <http://www.medicalveritas.com/AKrigsman.pdf>
- Evaluation, Diagnosis, and Treatment of Gastrointestinal Disorders in Individuals With ASDs: A Consensus Report — from AAP in 2009
- http://pediatrics.aappublications.org/content/125/Supplement_1/S1.full

2012 Articles from the AAP

- Gastrointestinal Conditions in Children With Autism Spectrum Disorder: Developing a Research Agenda
- http://pediatrics.aappublications.org/content/130/Supplement_2/S160.full
- Management of Constipation in Children and Adolescents With Autism Spectrum Disorders
- http://pediatrics.aappublications.org/content/130/Supplement_2/S98.full

Important New Information from AAP Articles

- Acknowledge the important role of GI conditions in ASDs and their impact on children as well as their parents and clinicians
- Acknowledge the gut-brain connection, immune function, and genome-microbiome interaction
- Increasingly, evidence supports a combination of changes in gut microflora, intestinal permeability, inappropriate immune response, activation of specific metabolic pathways, and behavioral changes
- Endoscopic analyses of children with ASD and GI symptoms have revealed the presence of a subtle, diffuse inflammation of the intestinal tract

Important New Information from AAP Articles

- Autoimmune responses in children with ASDs and a familial history of autoimmunity have been reported
- Autoantibodies could indicate the presence of inflammatory processes and/or an autoimmune component that could affect the integrity of the mucosal barrier and contribute to decreased mucosal barrier integrity
- Mentions “leaky gut” and explains the research supporting this theory so that general pediatricians can understand and begin to believe it
- Nutritional status and nutrient intake are inextricably related in children with autism

Articles for Gastroenterologist

- Clinical Presentation and Histologic Findings at Ileocolonoscopy in Children with Autistic Spectrum Disorder and Chronic Gastrointestinal Symptoms
<http://www.la-press.com/clinical-presentation-and-histologic-findings-at-ileocolonoscopy-in-ch-article-a1816>
- Identification of Unique Gene Expression Profile in Children with Regressive Autism Spectrum Disorder (ASD) and Ileocolitis
- <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0058058>

Articles for Gastroenterologist

- Share these studies on intestinal flora
- Gastrointestinal Microflora Studies in Late-Onset Autism
http://cid.oxfordjournals.org/content/35/Supplement_1/S6.full
- Short-Term Benefit from Vancomycin Treatment of Regressive-Onset Autism
<http://www.ncbi.nlm.nih.gov/pubmed/10921511?dopt=Abstract>

Textbook Indications for Esophagogastroduodenoscopy

- Acid peptic disease
- Suspicion of inflammation (including infection); biopsy, brushing, and cytology examination
- Acute epigastric or upper quadrant pain
- Hematemesis or melena
- Dysphagia or odynophagia
- Caustic ingestion or foreign body ingestion
- Recurrent vomiting
- Therapeutic intervention
 - Cautery bleeding lesion
 - Stricture dilation
 - Foreign body removal

Textbook Indications for Colonoscopy

- Gastrointestinal hemorrhage
- Chronic diarrhea
- Suspected inflammatory bowel disease
- Cancer surveillance
 - Inflammatory bowel disease
 - Polyposis syndromes
- Therapeutic intervention
 - Polyp removal
 - Foreign body removal
 - Decompression of toxic megacolon
 - Dilatation of stricture
 - Caution of bleeding lesion

Be Prepared

- Keep a **current** list that includes
 - All physicians and contact information
 - All documented diagnoses; this may include your after-visit summary at pediatrician or other providers
 - All allergies — food, medication and environmental
 - All medications, including daily dose(s)
 - All supplements, including daily dose(s)
 - All medications and supplements that your child reacts adversely to
 - Anesthesia plan, if you have one

Be Prepared

- Update this list frequently
- Multiple family members should know location of this list
- Take this list with you when going to
 - Appointments with physicians
 - Procedures (endoscopy, MRIs, etc.)
 - Planned hospital stays
 - Emergency room
 - If possible, take multiple copies with you

**You don't want to go there,
You don't plan to go there,
But you might end up there ...
The Emergency Room**

Emergency Room

- The tetanus question comes up when in need of stitches or have puncture wound
- A tetanus vaccine: Td, DTaP are used for prevention; they do not help in an emergency situation
- Tetanus immunoglobulin

Emergency Room

- Initial contact with hospital personnel
- On your way to the ER, contact your primary medical physician and let them know what's happening
 - Remember you know your child best
 - Communicate how to minimize your child's stress
 - Clearly communicate your immediate medical concerns and observations
 - Bring someone with you, if possible

Emergency Room

- Be prepared
 - You may be there for a long time
 - You may be emotional
- Bring calming items
- Bring list of doctors, allergies, medications, supplements, etc.

While at the Emergency Room

- When speaking with ER staff, use established medical diagnoses that are under current treatment
- Any and all current diagnoses that your child carries needs to be documented and reviewed at the ER
- Review your baseline presentation of those diagnoses
- Example of what to say:
 - He has a diagnoses of GERD, eosinophilic esophagitis and non-specific enteritis, Crohn's like
 - With GI pain, he normally bites his arm and whines. Today he is doing those things, and he's been aggressive with me. It's different; it's like he has an appendicitis or something. The pain is different.
 - This example allows the medical professional to have a medical framework giving direction for further evaluation

Discharge from the ER

- Make sure report is sent to the pediatrician
- Request copies of tests and labs done during your visit to ER
- Within 24 to 48 hours after discharge from ER, you will receive a call; use this opportunity to give ER personnel feedback on your experience.

Anesthesia

- Article to read and share
- Anesthesia and the Autistic Child
http://www.autism.com/index.php/pro_anesthesia

Hospitalization

- Prepare your child ahead of time
 - Social stories
 - Visit the hospital before
 - Look at the facility on-line
- Bring food and drink in the hospital
- Medications and supplements while in the hospital
- List of doctors, allergies, medications and supplements
- Item(s) that give child sense of security

Hospitalization

- The “psych team”
- Psych team wants to address the “behavior”
- You understand that the behavior is the outward expression of an underlying medical issue
- Conversation needs to occur regarding all prior medical diagnoses and how they impact child's behavior

Dentist

- Mercury-free
- Allow you to skip fluoride treatments
- Special-needs friendly
- TACA Dental Overview of Dental Filling Material
<http://www.tacanow.org/family-resources/dental-overview-of-dental-filling-materials/>
- Biological dentists — ask Janice for link

Find a Biological Dentist

- http://www.holisticdental.org/find_holistic_dentist
- <http://iaomt.org/find-a-doctor/search-for-dentist-physician/>
- http://biologicaldentistrydirectory.com/?field_1=0&field_2=69&s=Enter+search+keywords&submit=Search+Site
- https://dentalwellness4u.hostasaurus.com/freeservices/find_dentists.html

Overall Advice

- Document everything as much as possible
- Digitally record (photo or video)
 - Rashes
 - Stool
 - Distention
 - Posturing
 - Vomit
 - Urine
 - Red ears
 - Dark circles under eyes
 - Hair loss
 - Tics
 - Seizures

Maintain Composure

- Always be polite
- Don't raise your voice
- Don't use profanity
- Be prepared
- Be articulate
- Do not be afraid to ask questions

Networking with Other Parents

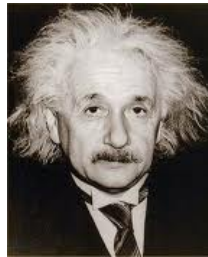
- TACA-USA yahoo group
 - <http://health.groups.yahoo.com/group/taca-usa/>
- Autism Research Institute yahoo group
 - <http://health.groups.yahoo.com/group/ARIsupport/>
- Autism Insurance Information yahoo group
 - http://health.groups.yahoo.com/group/autism_insurance_information/

Caution Is the Better Part of Valor

- Use physicians inside and outside of the autism community
- Diagnosis and clinical documentation from medical providers outside the autism community offer protection

Every Moment Is an Opportunity

- In almost every mainstream medical setting there are opportunities to educate clinicians about autism and the medical conditions that are common to our children.
- Sometimes you change the world one person at a time.



Learn from yesterday,
live for today, hope for
tomorrow. The
important thing is not
to stop questioning.

Albert Einstein

Questions?

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