

Integrative Healthcare for Individuals  
with ASD: Infancy through  
adulthood.



Friday, September 26, 2008

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Treating Individuals with Autism:  
Have we missed something?

- Margaret L. Bauman, MD
- Massachusetts General Hospital

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## Pervasive Developmental Disorders

- Autism
- Asperger's Syndrome
- Rett Syndrome
- Childhood Disintegrative Disorder
- Pervasive Developmental Disorder - not otherwise specified.

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### DSM-IV Diagnosis - Autism

- Impaired social interaction
- Delayed and disordered language
- Isolated areas of interest

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### Infant Toddler Data

- Pointing response for communication
- Joint attention
- Imaginary play
- Visual gaze
- Head lag

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### Inconsistent Clinical Features

- Atypical prosody, intonation
- Echolalia, scripting, pronoun reversals
- Repetitive and stereotypic behavior
- Need for routine; difficulty with novelty
- Hypotonia, poor motor coordination
- Atypical information processing

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## Neurological Assessments of the Child with Autism

1. Obtain a medical and developmental history
2. Neurological examination and behavioral observation
3. Consider need for additional studies:
  - a. Chromosomal/DNA analysis
  - b. Electroencephalogram (EEG)
  - c. Imaging studies (MRI, CT)
  - d. Metabolic (blood/urine) studies

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## What have we been missing?

- Important to describe cognitive, behavioral, language and processing modalities in ASD.
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- But ASD may be more than a disorder of information processing, language and behavior.
- ASD children, adolescents and adults can and often do have medical issues that have largely gone unrecognized and unaddressed.

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## What is the definition of “behavior”?

- The manner in which an organism behaves in reaction to social stimuli or inner need.
- Observable activity in response to an external or internal stimulus.
- Anything that the organism does that involves action or response to stimulation.

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### What do we know?

- Research indicates that typically developing children often show elevated rates of problem behavior in association with physical illness.
- Physical illness is common in persons with developmental disabilities (DD).
- Studies have documented significantly higher rates of acute and chronic medical conditions in DD persons as compared to the general population.

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### What medical conditions have been documented?

- Problem behaviors have been linked to condition such as constipation, allergies, premenstrual syndrome, ear infections and urinary tract infections.
- Plausible explanation relates to degree of pain or discomfort experienced by the individual at the time rather than to the physical illness per se.

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### Monitoring pain & discomfort is a complex process

- DD persons often lack the the communicative and cognitive skills that would allow for the direct assessment of pain and discomfort using a patient scale, checklist and/or interview strategies.
- Recent data suggests that those with the most severe cognitive impairment and fewest communication skills are likely to experience the most pain over time (Breau et al., 2003)

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### Why have these been overlooked?

- 1) Longstanding assumptions among the medical community about what autism is and who ASD persons are. Abnormal behaviors often interpreted as “part of the autism”.
- 2) ASD individuals may not present with the same symptoms or “red flags” as their “neurotypical” peers. Medical history may not help us.
- 3) Many ASD persons cannot tell us if they hurt/are uncomfortable nor accurately localize discomfort.

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### Weak Insights into Overall Health Issues

- Difficult to see beyond cognitive or behavioral features of the disorder
- Limited research into physiology of other organ systems outside of the brain
- No vehicle for collaboration on health issues
- No uniform set of clinical measures or data base.

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### Associated Medical Concerns?

- Seizures
- Sleep disturbances -
- Headaches
- Gastrointestinal disorders
- Genitourinary
- Hormonal imbalance/endocrine dysfunction
- Metabolic Disorders

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### Seizures - are they real?

- Often hard to tell - presentation may be atypical
- Routine EEG may not be helpful
- More prolonged EEG by high quality lab may help - the study is only as good as the person who interprets it.
- Use of video monitoring, MEG, other.
- Use of video taping

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### Sleep Disorders

- Problems with sleep onset or staying asleep
- Is this coming from the brain (centers of arousal)?
- Is this due to GI disorder? Acid reflux?
- Is this a respiratory problem? Does the child mouth breath suggesting big tonsils/adenoids?
- Sensory integration issues - needs deep pressure?
- Allergies?

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### Gastrointestinal Disorders

- Chronic diarrhea or constipation
- Feeding/eating disorder
- Change in sleep patterns
- Parents concerned about food allergies, need for special diet, yeast
- Possible abdominal pain/discomfort
- Behavioral changes or increased severity.

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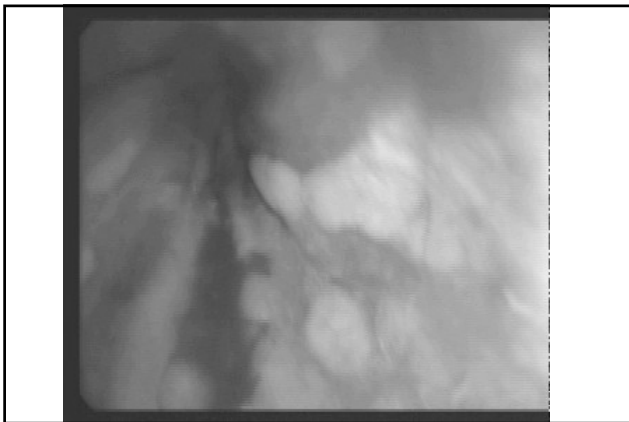
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**Neurotransmitters**

- Every known neurotransmitter present in the brain is present in the gut
- Acetylcholine, GABA, dopamine and serotonin have been connected with ASD
- All affect GI motility and sensitivity in a variety of ways.

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### Endocrine/Hormonal Disorders

- ASD girls whose behavior worsens with onset or during adolescence.
- Small subset with Congenital Adrenal Hyperplasia
- Should we also be looking at teenage ASD boys?

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### Reason for GU referral

- Previously continent child becomes incontinent
- Usually a preteen
- May be a “spastic bladder”
- Treatment with Ditropan may be helpful

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### “Red Flags” for Metabolic Work-up

- Poor physical endurance
- Late walking (i.e. 24 months)
- Repeated regressions after age 2 1/2 years
- Dysmorphic features
- Making poor progress despite excellent services
- Qualitatively “different”
- Involvement of multiple organ systems

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## Bullets

- ASD individuals need/deserve appropriate medical care.
- May not present with typical symptoms.
- Changes in behavior or prolonged episodes of behavioral abnormalities merit a medical look.
- Many of these disorders are treatable.
- We need to learn the language and signs of pain/discomfort in non-verbal and sensory impaired children.

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## The Autism Treatment Network (ATN)

Began in fall 2003. Modeled after LADDERS program

Originally consisted of five academic sites

– U. Wash (Seattle), Baylor, Columbia, OHSU, MGH

Involves multidisciplinary medical teams

Involves use of common protocols

Commitment to data sharing across/between sites

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## Why a consortium?

- Evaluate potential “red flags” - are they valid?
- Are there other “red flags” as yet to be identified?
- What proportion of ASD population affected?
- Accurate identification of medical disorders
- What interventions are most effective?
- Establish scientifically sound and meaningful standards of care

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### Why is this initiative important?

- Improve quality of life.
- If ASD persons feel better, they can take better advantage of services/therapies provided.
- Subsets of ASD persons may be more specifically identified - genetically and/or metabolically.
- Understanding associated medical conditions could enhance our understanding of the neurobiology of ASD.

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### Where are we now?

- In January 2007, Autism Speaks initiated a Request for Proposals - to expand the ATN initiative
- As a result, there are now a total of 15 multidisciplinary medical sites associated with academic centers. Combined centers met in LA in January 2008.
- Sites will provide high quality medical evaluation and care for ASD persons, share protocols and submit data into a common database.

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### Goals of the ATN

- To establish evidence based data with regard to medically related conditions in ASD.
- To establish standards of health care for children, adolescents and adults on the spectrum.

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