# Health Care for People of all ages with Autism

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# Overview

- DSM-5 Autism Spectrum Disorders
- Incidence
- Causes of ASD 'Epidemic'
- AAP Guidelines
- Diagnostic Workup
- Interventions and Medications
- Medical Home

# Autism Spectrum Disorders in DSM-5

A. Deficits in social communication and social interactions across a multiple contexts, as manifested by the following, currently or by history:
   1. Deficits in social emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions or affect; to failure to initiate or respond to social interactions
   2. Deficits in nonverbal communicative behaviors used for social interactions, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and using gestures; to a total lack of facial expressions and nonverbal communication.
   3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviors to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

# Autism Spectrum Disorders in DSM-5 cont.

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history:

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g. simple motor stereotypies, lining up of tows or flipping objects, echolalia, idiosyncratic phrases.)
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g. extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take some route or eat food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g. strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, aversive response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

# Autism Spectrum Disorders in DSM-5

C. Symptoms must be present in the early developmental period.

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnosis of autism spectrum disorder and intellectual disability, social communication should be below that of expected for general developmental level

# Autism Spectrum Disorders in DSM-5

- NOTE: those with a well-estabilished DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

# Autism Spectrum Disorders in DSM-5

- Specify if
  - With or without accompanying intellectual impairment
  - With or without accompanying language impairment
  - Associated with a known medical or genetic condition or environmental factor
  - Associated with another neurodevelopmental, mental, or behavioral disorder
  - With catatonia

# Severity Levels: Level 3 Requiring very substantial support

- **Social Communication:** Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches.

- **Restricted, repetitive behaviors:** Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty change focus or attention.

# Severity Levels: Level 2 Requiring substantial support

- **Social communication:** Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple-sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.

- **Restricted, repetitive behaviors:** Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or attention.

# Severity Levels: Level 1 Requiring support

- **Social communication:** Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interaction. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.

- **Restricted, repetitive behaviors:** Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

# Incidence

- 1 in 68
- M:F is 5:1
- Diagnosis can be reliable, valid, and stable as early as 2 years
- Average age of diagnosis is after 4$^{th}$ birthday

# Causes of Autism Epidemic?

- Genetics
- Diagnostic Substitution
- Testosterone
- TV
- Fetal Ultrasounds
- Advanced Paternal Age
- Leaky Gut Syndrome
- Vaccines?

# Vaccines

- 2 Theories; MMR and Thimerosal
- No evidence to support that these vaccines cause Autism
- 2001 Institute of Medicine review Epidemiological studies from US, Denmark, Sweden
- Many parents still blame vaccines

# Brain Abnormalities

- Decreased Purkinje cells in cerebellum
- Abnormal maturation of forebrain
- Frontal and temporal lobe abnormalities
- Brainstem abnormalities
- Macrocephaly (~1/3)
- Gray/White matter volume differences
- Connectivity/mirror neurons

# Genetics

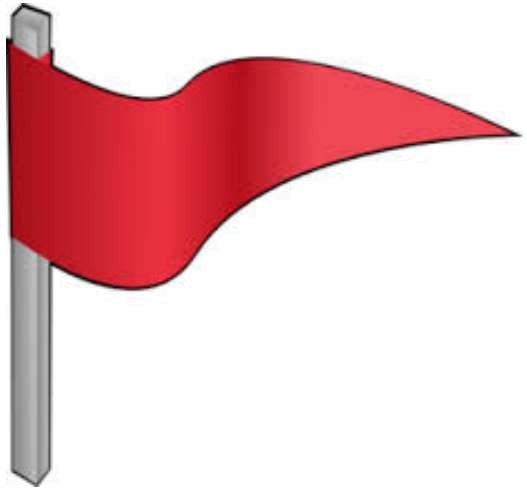
- 5-10% identifiable cause
- Abn chromosome 16, 22
- PTEN
- Mitochondrial disorders
- Fragile X
- Neurocutaneous syndromes
- Angleman/Prader Willi
- Rett Syndrome
- Smith-Lemli- Optiz

# AAP Guidelines

- Screen
  - General development at 9, 18 and 24 months
  - Autism specific at 18 and 24 months
- Evaluation
  - Audiology
  - EI/HMG
  - Referral

# Red Flags

- 12 months – no babbling
- 12 months – no pointing
- 24 months – no 2 word combinations
- Regression at any age



# Differential Diagnosis

- Communication Disorders; Language Disorder, Social (Pragmatic) Communication Disorder
- Global developmental delay/Intellectual Disability
- Stereotypic behavior disorder
- OCD
- ADHD
- Anxiety/Mood Disorder

# Diagnostic Workup

- Developmental Pediatrician/Psychologist/Psychiatrist
- History and Physical
- Standardized Tools
  - ADI-R
  - ADOS
- Assessment of cognition, language, and adaptive skills

# Medical Work-Up

- Chromosomes/Microarray/Fragile X
- Lead level
- Audiology
- Ophthalmology
- If needed – EEG, MRI

# Associated Medical Issues

- Feeding difficulties
- GI Issues (20-30%)
- Sleep
- Seizures (1/3 lifetime incidence)

# Effective Intervention Basics

- Entry at time of suspicion
- Intensive intervention (>25 hours/week)
- Year round
- low student-teacher ratio
- Family component
- Ongoing measurement
- Structure
- Generalization
- Focus on communication, social skills

# Evidence-Based Treatments

- Intensive Behavioral Interventions/Applied Behavioral Analysis
  - Early interventions
  - Intensive interventions
  - Comprehensive goals
  - Parental involvement
  - Successive, hierarchical teaching; “well-established” based on Chambliss criteria

# Medications in ASD

- ~50% treated with meds at some point in time
- Usage increases with age
  - Lower adaptive skills
  - Poorer social skills
  - Maladaptive behaviors
  - Residential placement

# Target Symptoms

- No medication that targets ASD specific symptoms
- Symptoms we can target through medication are:
  - Aggression
  - Irritability
  - Hyperactive
  - Attention
  - Obsessiveness

# Medications

- Risperidone
  - FDA approval for irritability, aggression
  - BID dosage up to 4 mg
- Other Atypicals
  - Aripiprazole
  - Quetiapine
  - Olanzapine
- Stimulants
  - Attention/Activity
  - 50-60% efficacy
  - Higher rate side effects
- SSRIs
  - Compulsive behaviors
  - Activation
  - Mood lability

# Rates of CAM and Autism

- Complementary and Alternative Medicines
- 50-75% of children with autism have been treated with CAM
- Versus 2-50% of children in US
- Sometimes before diagnosis is confirmed
- 75% think they are helpful

# Why more CAM in autism?

- Autism is chronic and pervasive
- Evidence-based treatments are expensive, difficult, on-going
- Available treatments often leave continued symptoms
- More frequent with co-morbid ID

# Motivations for CAM Consumers

- Claims of a “cure”
- Valid sounding psychological basis
- Important sounding, but vague benefits
- Stirring testimonials
- Backing of credentialed providers
- Backing of well-known proponents

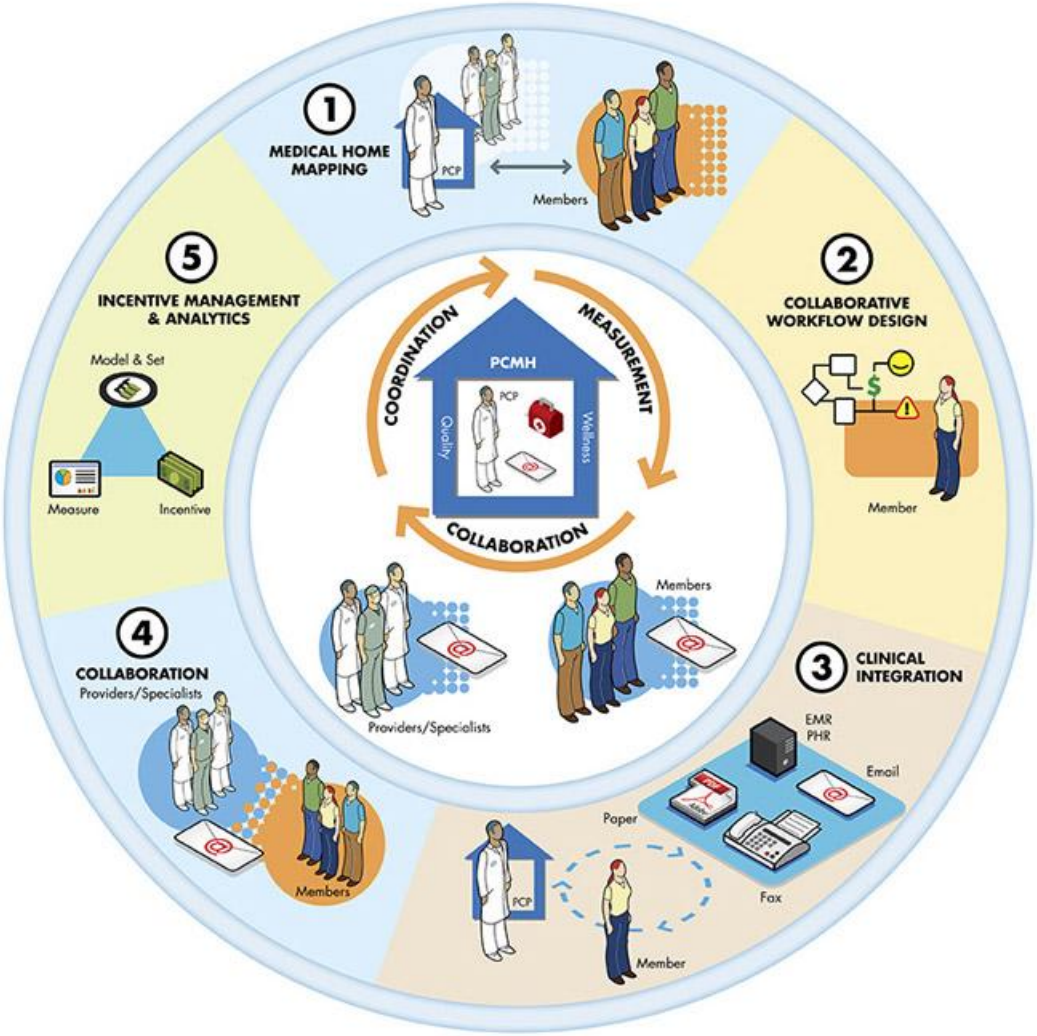
# Other Factors

- Hi tech tests or equipment
- No distinction between rigorous and non-rigorous science
- Anti-science bias
- Anti-establishment bias
- Subjective measures/evidence

# Types of CAM

- Gluten-free Casein-free diet
- Megavitamins and other supplements
- Hyperbaric Oxygen Treatment
- Chelation
- Secretin
- Craniosacral massage
- Sensory integration/auditory integration
- “DAN” protocol

# MEDICAL HOME


Patient-Centered Medical Home Management
1
MEDICAL HOME MAPPING
PCP
Members
2
COLLABORATIVE WORKFLOW DESIGN
Member
3
CLINICAL INTEGRATION
EMR
PHR
Email
Paper
Fax
PCP
Member
4
COLLABORATION
Providers/Specialists
Members
5
INCENTIVE MANAGEMENT & ANALYTICS
Model & Set
Measure
Incentive
COORDINATION
MEASUREMENT
COLLABORATION
PCMH
PCP
Quality
Wellness
Members
Providers/Specialists

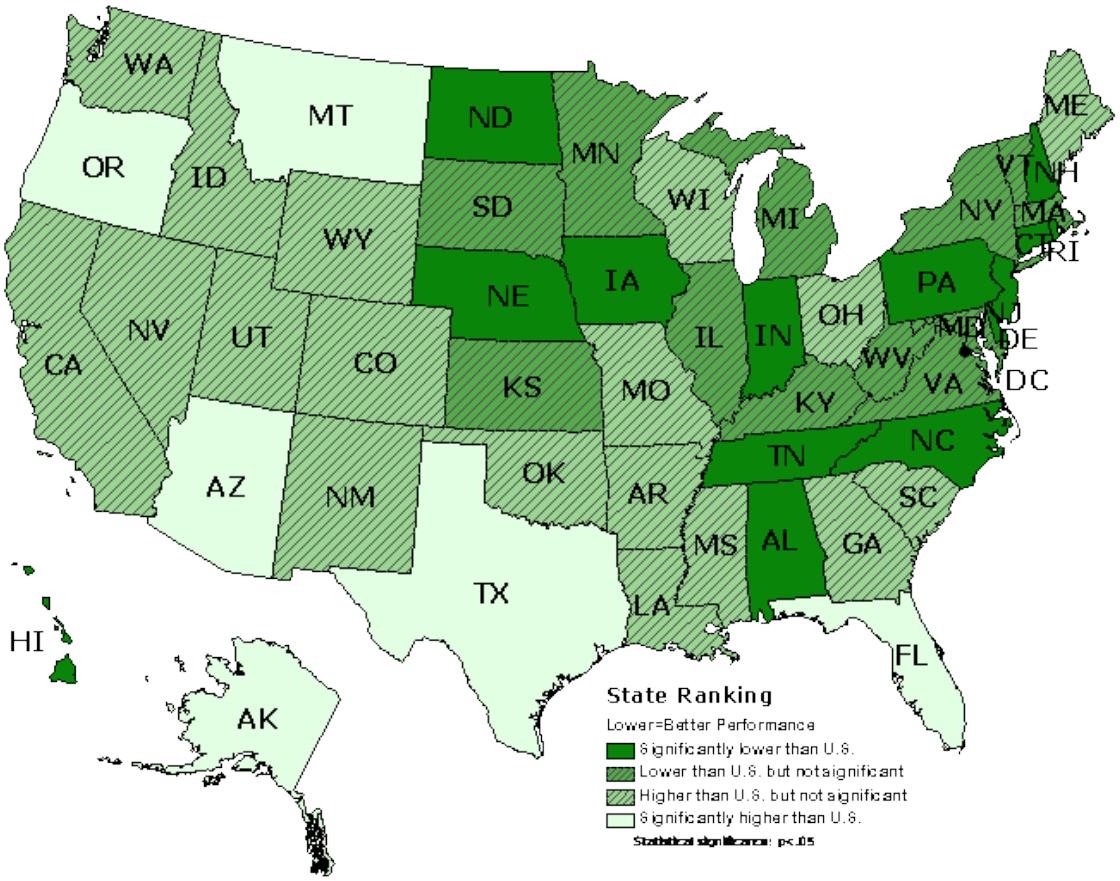
# Medical Home Care is:

- Accessible
- Comprehensive
- Family centered
- Continuous
- Care coordination
- Compassionate
- Culturally sensitive

# Benefits of Medical Home

- Increased patient/family satisfaction
- Forum for problem solving
- Improved care coordination
- More efficient, effective care
- Better use of limited resources
- Enhanced health outcomes

# 58% Medical Homes



# Good Care Through The Years

- Developmental Screening
- Comprehensive care
- Coordination
- Transition
- Routine screening

# WHAT YOU SAY MATTERS

- “Child with autism” NOT “autistic child”
- “Has autism” NOT “suffers from autism”
- Intellectual Disability NOT Mentally Retarded

# WHAT YOU DO MATTERS

- Talk to the person, even if they're non-verbal
- Shake hands (if part of your standard routine)
- Adapt physical exam as necessary
- End on a high/positive note
- Don't underestimate what you can do

# HOW YOU DO IT MATTERS

- Treat each person as individual
- Don't make assumptions
- If you don't know, ask!
- Don't give up

# Thank you

- Thank you for visiting the Autism Curriculum Guide website as part of the Nisonger Center.