

Diagnostic and Medical Evaluation, Intervention, and Office Visits for Children on the Autism Spectrum

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“I think a training should include what to look for for early diagnosis, the latest research on what therapies help, local resources available and how to access local services, as well as how to access funds for these services. Hopefully we can have a training locally. “

(parent of a child with autism)

When an autism spectrum disorder (ASD) is suspected...

- Refer to the CDS for developmental assessment to determine eligibility for services
- Refer to a clinician who can diagnose ASDs

Providers who can do diagnostic evaluations for ASDs in Maine

- **Developmental and Behavioral Pediatricians**
 - Evergreen Behavioral Health Child Development Center, Dr. Iris Silverstein, Farmington, 778-0035
 - Edmond Ervin Pediatric Center, Dr. John Salvato, Waterville 872-4303
 - York County PEDS Clinic, Dr Don Burgess, 467-6982
 - Eastern Maine Medical Center, Drs. Ellen Gellerstedt and Joanna Dotts, Bangor, 973-7520
 - MMC (Maine Medical Partners Pediatric Specialty Care) 662-1622, Drs Hubbard, Dalzell, Rock
- **Pediatric Neurologists**
 - Stephen Rioux, MD, Peter Morrison, MD 883-1414
- **Child and Adolescent Psychiatrists**
 - Autism, Developmental Disabilities and Early Childhood Clinic MMC 761-6644, option 2
- **Child Psychologists and Neuropsychologists**

What to expect from a diagnostic evaluation

- History from parents and childcare/ school staff
- Review of DSM-IV criteria
- +/- standardized questionnaire data on behavior, emotional and social development
- Assessment of adaptive functioning
- Review of medical history, including PCP records
- Observation of the child
- +/- Autism Diagnostic Observation Schedule (ADOS)
- Possibly speech and language evaluation
- Possibly cognitive assessment

Standard Medical Evaluation

- Audiological Evaluation – all children with language delay including ASDs
- AAP recommends high resolution chromosomes and fragile x studies in children with ASDs, especially those with global DD/MR
- Lead – especially if PICA, may contribute to delays in cognition and self-regulation

More Specialized Medical Evaluation

- EEG if signif regression or possible seizures
- Consider MRI with significant regression, microcephaly, neurocutaneous lesions, focal neuro exam, seizures
- Further laboratory studies
 - Microarray analysis (comparative genomic hybridization)
 - MECP2 testing for Rett Syndrome in girls with microcephaly, handwringing, regression
 - Metabolic work-up: , hypotonia, lethargy, poor growth, odors, ataxia, cyclic vomiting, dysmorphic features, newborn screening unknown, evidence of storage disease (eg, coarse features)
- Vision assessment

Management and follow-up care- what parents say...

“The doctors need to put judgment and expectation aside. They will see parents who are sleep-deprived and scatterbrained. They also need to make sure their staff are non judgmental. ”

Intervention: AAP Autism Toolkit

Physician Handouts:

Adolescence and Transition to Adulthood, Behavioral Issues, Complimentary and Alternative Medicine, Dietary Treatments, Eating and Nutrition, Gastrointestinal Problems, Psychopharmacotherapy, Seizures and Epilepsy, Sleep Disorders, Toilet Training

www.aap.org (bookstore section)

Myers S, Johnson CP. Management of Children with Autism Spectrum Disorders. *Pediatrics*. 2007; 120: 1162-1182.

“Speaking from an advocate's perspective, I think it's important for physicians to know their role in making sure parents know about special education services. Parents are usually in shock when they first receive the news that their little angel is disabled and often don't know the next steps in terms of asking for either CDS or school evaluations. I speak from personal experience in that even after we received the diagnosis that our son was autistic, no one told us about having him evaluated by CDS. This was something we ultimately were told by a pre-school teacher. “

(Parent of a child with autism)

Educational Intervention

- CDS or school system
- Special Education Classification (IDEA 2004) for “specially designed instruction”
- Appropriate classroom placement (level of support, peers, materials)
- Assessment of cognition and learning levels
- Speech, occupational, +/- physical therapy

- Recent lawsuit reinforced MaineCare payment for services that are “medically necessary” but not covered/recommended by CDS.
- Call the OMS Prior Authorization Unit Help Line 1-800-321-5557, Option 5

Educational approaches

- Applied Behavioral Analysis
- Social Cognitive therapy (Michele Garcia Winner)
- Relationship and play-based (Floortime, RDI)
- Visual supports (Carol Gray's Social Stories, Comic Strip Conversations)
- Augmentative Communication (PECS, voice output devices)
- Sensory supports and breaks
- In home support ("Katie Beckett" funding, Sections 24 or 65 of Maine Care,)

Medical Intervention

- Sleep
- Gastrointestinal issues (constipation, inflammation)
- Chronic pain (teeth, skin, headaches, menstrual cycle)
- Nutrition
- Comorbid behavioral health issues: anxiety, mood, executive dysfunction
- Integrative Medicine
 - **Used by 57 to 75% of families of children with ASDs**

Integrative Medicine

- Omega 3 fatty acids
- Melatonin
- Vitamin D
- Mind-Body techniques (hypnosis, biofeedback, relaxation)
- Body-based (chiropractic, massage, CST)
- B vitamins
- Probiotics
- Special diets (Gluten-free, casein free)
- Hyperbaric oxygen
- Chelation therapy
- Antibiotics (anti-fungal, bacterial, viral)

Working with children with ASDs during office visits

- Talk with the parents in advance
 - Prepare the child before the visit with a 'social story' or photos
 - Bring comfort items
 - Have parents stay with the child
- Schedule a practice visit
- Prepare staff
 - Defer vitals if uncomfortable
 - Do not approach the child too closely, or physically, watch for signs of distress/discomfort

Office visits, continued

- Minimize waiting, and physical intervention
- Recognize that behaviors may be due to ASDs (rigidity, anxiety) and not to deliberate oppositionality
- Recognize the role of sensory issues (fluorescent lights, crowded waiting room)

What parents of ME children with ASDs say about office visits

- “Wait room times – if they are long can cause escalation”
- “A lot of Pediatric offices have bright colors and toys – most kids enjoy this but our population can find that over stimulating”
- “I always say to my doctor when we arrive if we can be put into a examine room as soon as possible that helps cut down on both of the above problems. We don’t need to be seen right away but taken out of the wait room environment.”

More comments on office visits

“The doctors could make sure that the lights are not too bright for those that have sensory issues. Maybe a sheet on the tables for those who do not like the paper (the feel of it on their skin or the sound it makes). If there are going to be shots the parents should be told ahead of time so that the child can be told ahead of time, they should be able to bring their "safe" item. For my son it is his jacket. If they have a stress ball or some gadget to distract them so they don't get bored or stressed. Make sure the child's parents are there so that they feel secure.”

References

- Johnson CP, Myers SM. **Identification and Evaluation of Children with Autism Spectrum Disorders.** *Pediatrics.* 2007; 120: 1183-1215
- Levy S and Hyman S. Complementary and Alternative Medicine Treatments for Children with Autism Spectrum Disorders. *Child Adol Clin N Amer,* 2008, 17:803-820
- Myers S, Johnson CP. **Management of Children with Autism Spectrum Disorders.** *Pediatrics.* 2007; 120: 1162-1182.

Internet Resources

- www.firstsigns.org Parent-generated site with video library and extensive info on screening tools for ASDs
- <http://www.cdc.gov/actearly> Excellent site on general developmental screening, milestones and disorders
- www.nichcy.org National Dissemination Center for Children with Disabilities. Good fact sheets on many conditions and issues
- http://www.autismresearchcentre.com/tests/cast_test.asp British site with CAST Asperger screening instrument available
- www.asmonline.org Autism Society of Maine: lending library, information specialists, conference schedule, summer camp, advocacy efforts
- www.thegraycenter.org Social stories and more
- www.aap.org Go to bookstore section for Autism Toolkit
- www.futurehorizons-autism.com/ Catalog with many books and other resources on ASDs