



Medical Home Newsletter

Screening and Ongoing Care for Children with Autism

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www.medicalhomeportal.org

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Welcome

This publication aims to support health care providers in establishing and maintaining Medical Homes for their pediatric patients by providing useful information and tools.

To offer comments, suggest ideas for future newsletters contact the Project Coordinator, Barbara Ward, RN barbarward@utah.gov

Copies of past newsletters may be found on the Medical Home Portal: www.medicalhomeportal.org

Role of Medical Home in Autism Spectrum Disorders (ASD)

- Surveillance and Screening
- Diagnosis
- Long Term Management

“ASDs are a group of related disorders characterized by impairments in social interaction and communication and the presence of ritualistic and stereotyped behavior.” The exact cause is unknown but there is a 5-6% recurrent rate in families and in a minority of cases may be associated with a medical condition or genetic syndrome. The US prevalence is 1 in 110 of all children and the male to female ratio is 4:1. Symptoms of ASDs are present from the first year of life for most children however the average age at diagnosis is 4 years.

The greatest impact for intervention occurs if the intervention starts when concerns are identified.

Rationale for early diagnosis

- Early intensive intervention may result in better outcomes
- “Wait and See” approach can result in parental discontent and anger
- Allows for genetic counseling regarding the a risk of recurrence

Surveillance and Screening for ASD’s

Surveillance involves taking a thorough family history, listening to parents and looking for the early signs which include:

- Language delay or odd use of language
- Restricted and or repetitive interests or behaviors
- Early social skill deficits in joint attention, social orienting and pretend play

Deficits in joint attention are the most distinguishing characteristics of very young children with autism and include the act of engaging another’s attention to regard objects, events, or other persons simply for the enjoyment of experience sharing.

Social orienting is the ability to orient and acknowledge a verbal bid for attention. A child should respond to their name by 9-12 months at least half the time. Parents may be concerned that the child has hearing problems because of lack of orienting to name.

Pretend play is the ability to transform objects and actions symbolically and involves social dialogue, role taking and improvisation. Young children with autism have little interest in toys, if interested in toys they tend to pay more attention to parts rather than the whole. Ask the parent at the 15, 18 or 24-month visit about favorite toys and manner of play.

To probe for language deficits, at the 9-12 month visits look for absent or atypical babbling and unusual vocalizations. At the 15, 18, 24 month visit look for delays in expressive or receptive language milestones, regression, echolalia or exceptional labeling skills. Early deficits in social skills are the basis for later deficits in initiating and sustaining conversation.

Surveillance also involves noting at the 12, 15, 18, 24 month visit any unusual attachments (comfort item in the office), stereotypic movements or severe tantrums precipitated by transition.

Screening

Even with careful surveillance some children can be missed, therefore an autism specific tool should be administered to all children at the 18 and 24-month visit, making referral decisions easier. Tools that are designed more broadly for developmental disorders have not been adequately tested for ASDs.

Screening Tools

Currently there are not many tools available.

The Modified Checklist for Autism in Toddlers (M-CHAT) consists of 23 yes/no items completed by parents, takes only 5-10 minutes to complete, easy to score, is available in multiple languages and is free <http://www2.gsu.edu/~psydlr/>.

This is a two-step tool. For those who fail on the first screening, some recommend screening one month later or following-up with the structured interview (available for download) to prevent false positives and unnecessary referrals. Physicians use the M-CHAT at the 18 and 24-month visit. Failure rate is estimated at 2 failures per provider per month resulting in 2 extra visits. (Kleinman, 2008)

The Communication and Symbolic Behavioral Scales Developmental Profile (CSBS DP) available free <http://www.brookespublishing.com/store/books/wetherby-csbsdp/checklist.htm>

is based on parent report, should be used along with an observation by a health care provider and is used as a basis for further evaluation. This tool is appropriate to screen every three months from 6-24 months.

For preschoolers and school-age children use the **Childhood Asperger Spectrum (formerly Syndrome) Test (CAST)** available free <http://www.autismresearchcentre.com/arc/>

This tool is a 37-item parental self-completion questionnaire and was originally designed as a prevalence screen for Asperger syndrome but was found to be useful in lower functioning individuals as well.

When to Refer for confirmation of DX

Surveillance score 1 for each of the following factors and refer for >2 plus a failed screening tool

- Sibling with ASD
- Parental concern or other caregiver concern
- Primary care provider concern

A Positive Screen: What Now?

- Provide Parental education (see resources at end of newsletter)
- Simultaneous referrals:
 1. Comprehensive ASD Evaluation
 2. Audiology
 3. Early Intervention for <3yo or Special education for >3yo
- Schedule follow-up visit

A comprehensive ASD evaluation should consist of an interdisciplinary team and involve:

- A comprehensive health, developmental and behavioral history
- Physical examination
- Developmental and/or psychometric evaluation
- The presence of criteria from the DSM-IV
- A laboratory evaluation for a known etiology or coexisting condition
- Team members may include a Developmental Pediatrician, Geneticist, Neurologist, Audiologist, Occupational Therapist, Speech/Language Pathologist, Social Worker and Child Psychiatrist
- Assessment of parents' knowledge of ASD's, available resources and supports

Diagnostic evaluations in Utah

1. **Child Development Clinic** at the Children with Special Health Care Needs (CSHCN) Salt Lake City, Birth-Eight
801-584-8510 or toll free 800 829-8200
<http://health.utah.gov/cshcn/>
2. **University of Utah Child and Adolescent Specialty Clinic**, University of Utah, Salt Lake City
801-585-1212
<http://healthcare.utah.edu/UNI/services/youth/childAdolescent.html>
3. **CSHCN Satellite clinics**, Ogden, Vernal, Richfield, Price, Moab, St George, Blanding
801-584-8510 or toll free 800 829-8200 or check website for individual clinic numbers
<http://health.utah.gov/cshcn/>
4. **Children's Center**
Salt Lake City 801- 582-5534
Kearns 801- 966-4251
www.tccslc.org/index.html

For OT/PT and Speech evaluations

Primary Children's Clinics
Bountiful 801-292-8665
Ogden 801 387-2080
Sandy 801-571-3081
Taylorsville 801-840-4360

PCMC website:

<http://intermountainhealthcare.org/hospitals/primarychildrens/services>

For private providers see the Medical Home Portal Services section

www.medicalhomeportal.org or

the Autism Council website

<http://www.autismcouncilofutah.org/>

Long Term Management

Schedule a follow-up visit shortly after the evaluation to discuss concerns

Look for co-morbid conditions

Educate parents and provide up-to-date information

Refer to local community resources

Parent and Provider Information:

Caring for Children With Autism Spectrum Disorders: A Resource Toolkit for Clinicians

Available free at:

<http://www.aap.org/publiced/autismtoolkit.cfm>

from the American Academy of Pediatrics

“This toolkit was developed to support health care professionals in the identification and ongoing management of children with autism spectrum disorders (ASDs) in the medical home”. The toolkit is an excellent source for parent education and includes handouts for the family as well as the practitioner.

The toolkit includes information on medical management and family information:

1. During Office Visits
2. During Dental Visits
3. Adolescence and Transition
4. Asperger Syndrome
5. Behavioral Principals
6. Complimentary and Alternative Medicine Therapies
7. Dietary Treatments/Eating and Nutrition
8. Gastrointestinal Problems
9. Psychopharmacology
10. Sibling Issues
11. Sleep Disorders
12. Toilet Training
13. Vaccines
14. Tips on Writing Letters of Medical Necessity

Office Materials

CDC has FREE materials for parents, healthcare providers, and childcare providers, called the Learn the Signs, Act Early Campaign. All materials are printed with English on one side and Spanish on the other.

<http://www.cdc.gov/ncbddd/actearly/freematerials.html>

Utah Resources for parents and providers

Baby Watch/Early Intervention (EI)

There are 16 local programs of EI in Utah available statewide. Services include:

- A full assessment of a child's current health and development status.
- Service coordination among providers, programs and agencies.
- Strategies to build on family concerns, priorities, & resources (CPR).
- Developmental services: occupational therapy, physical therapy, speech language therapy, etc.

Call 1-800-961-4226 or go to their website for local contact information

<http://www.utahbabywatch.org/>

For an application go to the medical home portal or

Utah clicks. www.utahclicks.com

Autism Council of Utah

****Excellent source for Utah Resources****

The Autism Council of Utah is an independent council working to foster collaboration, communication, and learning among families and agencies.

<http://www.autismcouncilofutah.org/>

Autism Information Resources at the Utah Parent Center

2290 East 4500 South, Suite 110

Salt Lake City, UT 84117

(801) 272-1051; (800) 468-1160 (V/TTY)

Web: www.utahparentcenter.org

Big MAK's (Mothers of Autistic Kids)

“More support than a 44DD”

This is a group of parents and their children on the spectrum that meet every 2nd Monday of each month from 6-8 p.m. at Bouncin Off the Walls contact Cheryl Smith at smithfam29@msn.com.

University Centers for Excellence in

Developmental Disabilities:

Autism Support Services: Education, Research, and Training (ASSERT) provides services to preschool children with autism and to their families Center for Persons with Disabilities, USU, Logan, UT

(435) 797-1987 www.cpd.usu.edu

Utah State Office of Education

Programs for Children with Disabilities 3-5 years old contact Connie Nink (801) 538-7948

www.schools.utah.gov/sars/preschool.htm

Information taken from Paul Carbone's presentation to UPIQ Learning Session June 12, 2009