Navigating Services for Young Children with Autism Spectrum Disorder (ASD)

A Michigan Guide for Professional Services

March 2012

To access this and other documents on ASD, go to:

ddi.wayne.edu
# Table of Contents

**Professional ASD Referral Overview**  
Process Flow .......................... 3

**Identification and Evaluation**  
Medical Management and Further Evaluation  
When ASD is Confirmed .......................... 4  
Key Considerations for Primary Care Physician .......................... 4

**Diagnostic Criteria**  
Diagnostic and Statistical Manual (DSM-IV) .......................... 5

**Modified Checklist for Autism in Toddlers (M-CHAT)**  
Instructions and Permission for use of M-CHAT .......................... 8  
M-CHAT Scoring .......................... 8  
M-CHAT Questions .......................... 8

**Resources**  
Resource Names and Contact Information .......................... 9
Professional ASD Referral Overview

WELL CHILD VISIT

When: Every well-child visit
Who: Primary Care Provider (PCP)
Does What: Monitoring Development

Developmental Concern
Initiated by: Parent, Caregiver, Teacher, Physician

Outcome: Identifies signs/risks for Developmental Disability/ASD

Action:
1. Further evaluation by PCP or refer to Early On® for other in-depth evaluation
2. Refer to Early On and/or specialist for full ASD assessment

UNIVERSAL SCREENING WITH QUESTIONNAIRE (MCHAT)

When: 18 and 24 (or 30) Months
Who: Primary Care Provider (PCP)
Does What: Identifies Signs/Risks for ASD or Other Developmental Disability

Outcome: Identifies signs/risks for Developmental Disability/ASD

Action:
1. Refer to Early On and/or specialist for full ASD Assessment

ASD ASSESSMENT

When: Specialty Consult
Who: Multi-disciplinary Medical Team or Individual Specialist
Does What: Medical Diagnosis/Other Diagnosis/No Diagnosis

Action:
1. Refer to EarlyOn Support Services (speech, occupational therapy, special education)
2. Refer to local Community Mental Health (CMH)
Identification and Evaluation

In 2007, the American Academy of Pediatrics (AAP) published a policy statement on the identification and evaluation of children with autism spectrum disorder. This very helpful document is available online: [http://aappolicy.aappublications.org/cgi/content/full/pediatrics;120/5/1183](http://aappolicy.aappublications.org/cgi/content/full/pediatrics;120/5/1183).

The process for identification is summarized in the previous flow chart. In addition, the following red flags are highlighted:

- No babbling or pointing or other gesture by 12 months of age
- No single words by 16 months of age
- No 2-word spontaneous (not echolalic) phrases by 24 months
- Loss of language or social skills at any age

The presence of any of these red flags warrants an immediate evaluation.

Comprehensive evaluation for a child suspected of having an ASD is ideally provided by a multidisciplinary team of experts. Unfortunately, not all children have access to such a team. The evaluation can be completed by individual experts such as behavior and developmental pediatricians, pediatric neurologists, child psychiatrists, and pediatric psychologists. Some primary care physicians have additionally developed skills in diagnosing ASD.

Medical Management and Further Evaluation when ASD is Confirmed

The AAP also published a policy statement on the management of children with ASD which is available at: [http://aappolicy.aappublications.org/cgi/content/full/pediatrics;120/5/1162](http://aappolicy.aappublications.org/cgi/content/full/pediatrics;120/5/1162).

The health care needs of children with ASD are most appropriately met in the context of a medical home. The history, approach to the patient, physical examination, and treatment options must be considered in the context of the patient’s ASD. The PCP may consider:

- Extending the office visit
  - Opportunities to familiarize patient with office & staff prior to visit
  - Slowing pace of visit
  - Using visual cues

Key Considerations for PCP:

- Routinely inquire about both medical and nonmedical alternative therapies or interventions the patient/family are using or considering (alternative diets, nutritional supplements, chelation therapy, etc.); PCP should provide perspective on risks verses benefits of all medical and nonmedical alternative therapies.
- Work in partnership with families to evaluate therapy options and develop specific timelines of intervention and discrete treatment goals/objectives.
- Comprehensive evaluation and management of children with ASD will include a genetic evaluation, especially ASD associated with cognitive/intellectual disability, dysmorphology, clinical features (large head), etc.
- Assess and provide anticipatory guidance for development of seizures; presence of seizures or regression in developmental skill warrants referral to neurologist; always include seizures in the differential when new difficult behaviors arise.
- Evaluate and provide guidance for feeding difficulties; consider a differential for feeding difficulties (GERD, oral motor dysfunction, dental pain, lactose intolerance, etc) and not immediately attribute feeding difficulties to the ASD; have understanding of potential nutritional deficiencies (iron, zinc, vitamin D deficiencies) that may arise from restricted dietary styles; specialized feeding difficulties may require referral to a specialist; always inquire about nutritional supplements or alternative diets being practiced.
- Regularly ask about sleeping difficulties (sleep refusal, delayed onset, nighttime awakening, early morning arousal, restless/active sleep. etc.) as one third to one half of children with ASD have sleep difficulties.
- Maintain high index of suspicion and provide anticipatory guidance for co-morbid psychiatric disorders (Mood Disorders, Anxiety Disorders, ADHD, Tourette’s Syndrome).
DIAGNOSTIC CRITERIA

Diagnostic and Statistical Manual (DSM-IV)

Note: Current DSM criteria; revised (pending) criteria for DSM-V provided below; proposed adaptation for 2013.

The Diagnostic and Statistical Manual of Mental Disorders (DSM) is published by the American Psychiatric Association and utilizes common language and standard criteria to classify mental disorders. The DSM has been revised a number of times with the latest being DSM-IV published in 1994. The DSM-V is currently in preparation with a yet to be determined final release date. Autism and related disorders are defined clinically by the DSM-IV. Note that a number of revisions are pending for the Autism diagnosis in DSM-V. To review information on the DSM, go to: http://www.psyweb.com/DSM_IVjsp/dsm_iv.jsp.

Pervasive Development Disorders: 299.00 Autistic Disorder

A. Total of six or more items from (1), (2), and (3); at least two from section (1) and one from both (2) and (3).

(1) qualitative impairment in social interaction, as manifested by at least two of the following:
   a) marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
   b) failure to develop peer relationships appropriate to developmental level
   c) lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (lacks showing, bringing, pointing out items of interest)
   d) lack of social or emotional reciprocity

(2) qualitative impairments in communication, as manifested by at least one of the following:
   a) delay in, or complete lack of, the development of spoken language (no attempt to compensate in communication with alternate methods of communication including gestures or mime)
   b) in individuals with adequate speech, market impairment in the ability to initiate or sustain a conversation with others
   c) stereotyped and repetitive use of language or idiosyncratic language
   d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities as manifested by at least one of the following:
   a) encompassing preoccupations with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity of focus
   b) apparently inflexible adherence to specific, nonfunctional routines or rituals
   c) stereotyped and repetitive motor mannerisms (hand or finger flapping, twisting, or complex whole-body movements)
   d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett’s disorder or childhood disintegrative disorder.
**DSM-IV Continued**

**Pervasive Development Disorder: Not Otherwise Specified: (PDD-NOS): 299.80**
This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present, but the criteria are not met for a specific pervasive developmental disorder, schizophrenia, schizotypal personality disorder, or avoidant personality disorder.

**Asperger’s Disorder: 299.80**
A. Qualitative impairment in social interaction, as manifested by at least two of the following:
   (1) marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
   (2) failure to develop peer relationships appropriate to developmental level
   (3) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
   (4) lack of social or emotional reciprocity
B. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities as manifested by at least one of the following:
   (1) encompassing preoccupations with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity of focus
   (2) apparently inflexible adherence to specific, nonfunctional routines or rituals
   (3) stereotyped and repetitive motor mannerisms (hand or finger flapping, twisting, or complex whole-body movements)
   (4) persistent preoccupation with parts of objects
C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
D. There is no clinically significant general delay in language (e.g. single words used by 2 years, communicative phrases used by age 3 years)
E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
F. Criteria are not met for another specific pervasive development disorder or schizophrenia.

*For additional information on Rett’s Disorder and Childhood Disintegrative Disorder, go to the DSM-IV at: [http://www.psyweb.com/DSM_IV/isp/dsm_iv.jsp](http://www.psyweb.com/DSM_IV/isp/dsm_iv.jsp).*
Instructions and Permissions for Use of the M-CHAT

The Modified Checklist for Autism in Toddlers (M-CHAT); (Robins, Fein, & Barton, 1999) is available for free download for clinical, research, and educational purposes. There are two authorized websites: the MCHAT and supplemental materials can be downloaded from www.firstsigns.org or from Dr. Robins' website, at http://www2.gsu.edu/~psydlr/Diana_L_Robins_Ph.D_files/M-CHAT_new.pdf.

Furthermore, the M-CHAT is a copyrighted instrument, and use of the M-CHAT must follow these guidelines: (1) Reprints/reproductions of the M-CHAT must include the copyright at the bottom © 1999 Robins, Fein, & Barton. No modifications can be made to items or instructions without permission from the authors; (2) The M-CHAT must be used in its entirety. There is no evidence that using a subset of items will be valid; (3) Parties interested in reproducing the M-CHAT in print (e.g., a book or journal article) or electronically (e.g., as part of digital medical records or software packages) must contact Diana Robins to request permission (drobins@gsu.edu).

Instructions for Use

The M-CHAT is valid for screening toddlers between 16 and 30 months of age, to assess risk for autism spectrum disorders (ASD). The M-CHAT can be administered and scored as part of a well-child check-up, and also can be used by specialists or other professionals to assess risk for ASD. The primary goal of the M-CHAT is to maximize sensitivity, meaning to detect as many cases of ASD as possible. Therefore, there is a high false positive rate, meaning that not all children who score at risk for ASD will be diagnosed with ASD. To address this, the authors developed a structured follow-up interview for use in conjunction with the M-CHAT; it is available at the two websites listed above. Users should be aware that even with the follow-up questions, a significant number of the children who fail the M-CHAT will not be diagnosed with an ASD; however, these children are at risk for other developmental disorders or delays, and therefore, evaluation is warranted for any child who fails the screening.

Scoring

The M-CHAT can be scored in less than two minutes. Scoring instructions can be downloaded from http://www2.gsu.edu/~psydlr/Diana_L_Robins_Ph.D_files/M-CHAT_score.pdf or www.firstsigns.org. The scoring template is available on these websites. When printed on an overhead transparency and laid over the completed M-CHAT, it facilitates scoring. (http://www2.gsu.edu/~psydlr/Diana_L_Robins_Ph.D_files/M-CHAT%20scoring%20template.pdf).

A child fails the checklist when 2 or more critical items are failed OR when any three items are failed. Yes/no answers convert to pass/fail responses. Below are listed the failed responses for each item on the M-CHAT. Bold capitalized items are CRITICAL items.

<table>
<thead>
<tr>
<th>Item</th>
<th>Response</th>
<th>Item</th>
<th>Response</th>
<th>Item</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>No</td>
<td>7.</td>
<td>NO (Critical)</td>
<td>13.</td>
<td>NO (Critical)</td>
</tr>
<tr>
<td>2.</td>
<td>NO (Critical)</td>
<td>8.</td>
<td>No</td>
<td>14.</td>
<td>NO (Critical)</td>
</tr>
<tr>
<td>3.</td>
<td>No</td>
<td>9.</td>
<td>NO (Critical)</td>
<td>15.</td>
<td>NO (Critical)</td>
</tr>
<tr>
<td>5.</td>
<td>No</td>
<td>11.</td>
<td>Yes</td>
<td>17.</td>
<td>No</td>
</tr>
<tr>
<td>6.</td>
<td>No</td>
<td>12.</td>
<td>No</td>
<td>18.</td>
<td>Yes</td>
</tr>
<tr>
<td>19.</td>
<td>No</td>
<td>20.</td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21.</td>
<td>No</td>
<td>22.</td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23.</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Please fill out the following about how your child usually is. Please try to answer every question. If the behavior is rare (e.g., you have seen it once or twice), please answer as if the child does not do it.

1. Does your child enjoy being swung, bounced on your knee, etc.? Yes No
2. Does your child take an interest in other children? Yes No
3. Does your child like climbing on things, such as up-stairs? Yes No
4. Does your child enjoy playing peek-a-boo/hide-and-seek? Yes No
5. Does your child ever pretend, for example, to talk on the phone or take care of a doll or pretend with other things? Yes No
6. Does your child ever use his/her index finger to point, to ask for something? Yes No
7. Does your child ever use his/her index finger to point, to indicate interest in something? Yes No
8. Can your child play properly with small toys (e.g. cars or blocks) without just mouthing, fiddling, or dropping them? Yes No
9. Does your child ever bring objects over to you (parent) to show you something? Yes No
10. Does your child look you in the eye for more than a second or two? Yes No
11. Does your child ever seem oversensitive to noise? (e.g., plugging ears) Yes No
12. Does your child smile in response to your face or your smile? Yes No
13. Does your child imitate you? (e.g., you make a face—will your child imitate it?) Yes No
14. Does your child respond to his/her name when you call? Yes No
15. If you point at a toy across the room, does your child look at it? Yes No
16. Does your child walk? Yes No
17. Does your child look at things you are looking at? Yes No
18. Does your child make unusual finger movements near his/her face? Yes No
19. Does your child try to attract your attention to his/her own activity? Yes No
20. Have you ever wondered if your child is deaf? Yes No
21. Does your child understand what people say? Yes No
22. Does your child sometimes stare at nothing or wander with no purpose? Yes No
23. Does your child look at your face to check your reaction when faced with something unfamiliar? Yes No

© 1999 Diana Robins, Deborah Fein, & Marianne Barton
## Resources

<table>
<thead>
<tr>
<th>Resource Name</th>
<th>Online Contact Information</th>
<th>Telephone Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Association for Science in Autism Treatment (ASAT)</td>
<td><a href="http://www.asatonline.org">www.asatonline.org</a>.</td>
<td></td>
</tr>
<tr>
<td>American Academy of Pediatrics (AAP)</td>
<td><a href="http://www.aap.org">www.aap.org</a> (Search on Autism, Select AAP Children's Health Topics: Autism)</td>
<td>847-434-8000</td>
</tr>
<tr>
<td>American Academy of Pediatrics (AAP), Healthy Children.Org</td>
<td><a href="http://www.healthychildren.org">www.healthychildren.org</a> (Search on Autism)</td>
<td></td>
</tr>
<tr>
<td>Autism Alliance of Michigan</td>
<td><a href="http://www.autismallianceofmichigan.org">www.autismallianceofmichigan.org</a></td>
<td>313-964-2620</td>
</tr>
<tr>
<td>Autism NOW</td>
<td><a href="http://www.autismnow.org">www.autismnow.org</a></td>
<td>855-828-8476</td>
</tr>
<tr>
<td>Autism Society</td>
<td><a href="http://www.autism-society.org">www.autism-society.org</a></td>
<td>800-328-8476</td>
</tr>
<tr>
<td>Autism Speaks (Family Response Team)</td>
<td><a href="http://www.autismspeaks.org">www.autismspeaks.org</a></td>
<td>888-288-4762</td>
</tr>
<tr>
<td>Centers for Disease Control (CDC) (Autism Spectrum Disorders)</td>
<td><a href="http://www.Centers">www.Centers</a> for Disease Control.gov (Search on Autism)</td>
<td>800-232-4636</td>
</tr>
<tr>
<td>Early On®</td>
<td><a href="http://www.1800EarlyOn.org">www.1800EarlyOn.org</a></td>
<td>800-327-5966</td>
</tr>
<tr>
<td>Interactive Autism Network</td>
<td><a href="http://www.iancommunity.org/cs/home">www.iancommunity.org/cs/home</a></td>
<td></td>
</tr>
<tr>
<td>Michigan Alliance for Families</td>
<td><a href="http://www.michiganalliancefamilies.org">www.michiganalliancefamilies.org</a></td>
<td>800-552-4821</td>
</tr>
<tr>
<td>Michigan Department of Community Health (MDCH)</td>
<td><a href="http://www.michigan.gov/mdch">www.michigan.gov/mdch</a></td>
<td>517-373-3740</td>
</tr>
<tr>
<td>Michigan Department of Education (MDE) Early Childhood Special Education</td>
<td><a href="http://www.michigan.gov/mde">www.michigan.gov/mde</a> (Select Programs, then Early Childhood Special Education)</td>
<td>517-373-0485</td>
</tr>
<tr>
<td>Michigan Department of Education (MDE), Local School District Map</td>
<td><a href="http://www.michigan.gov">www.michigan.gov</a> (Search on Michigan School District Map)</td>
<td></td>
</tr>
<tr>
<td>Michigan Department of Education (MDE), Office of Great Start</td>
<td><a href="http://www.michigan.gov/mde">www.michigan.gov/mde</a> (Select Offices in left sidebar, select Great Start from table)</td>
<td>517-373-8483</td>
</tr>
<tr>
<td>Michigan Department of Human Services (MDHS)</td>
<td><a href="http://www.michigan.gov/dhs">www.michigan.gov/dhs</a></td>
<td>517-374-6472</td>
</tr>
<tr>
<td>Michigan Head Start</td>
<td><a href="http://www.michheadstart.org">www.michheadstart.org</a></td>
<td>517-374-6472</td>
</tr>
<tr>
<td>National Institutes of Mental Health (NIMH)</td>
<td><a href="http://www.nimh.nih.gov">www.nimh.nih.gov</a> (Search on Autism)</td>
<td>866-615-6464</td>
</tr>
<tr>
<td>National Dissemination Center for Children with Disabilities (NICHCY)</td>
<td><a href="http://www.nichcy.org">www.nichcy.org</a></td>
<td>800-695-0285</td>
</tr>
<tr>
<td>National Autism Center (NAC): National Standards Project (NSP)</td>
<td><a href="http://www.nationalautismcenter.org">www.nationalautismcenter.org</a> (Select National Standards Project in menu bar)</td>
<td>877-313-3833</td>
</tr>
<tr>
<td>National Professional Development Center (NPDC)</td>
<td><a href="http://www.autismpdc.fpg.unc.edu">www.autismpdc.fpg.unc.edu</a></td>
<td></td>
</tr>
<tr>
<td>Statewide Autism Resources and Training (START)</td>
<td><a href="http://www.gvsu.edu/autismcenter">www.gvsu.edu/autismcenter</a></td>
<td>616-331-6486</td>
</tr>
</tbody>
</table>
This document is supported by a grant from the Association of Maternal and Child Health Programs (AMCHP)

Grant# 2011-01-0127-14