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Surveillance and Screening for Autism Spectrum Disorders in Very Young Children

PHYSICIAN TOOLKIT

BASED ON THE CANADIAN BEST PRACTICE GUIDELINES

MIRIAM FOUNDATION 2008

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What are the Autism Spectrum Disorders (ASDs)?

ASDs represent a subgroup of the Pervasive Developmental Disorders (DSM-IV-TR), and include autistic disorder, Asperger's disorder, and pervasive developmental disorder – not otherwise specified (PDD-NOS). Approximately 1/166 children meet the diagnostic criteria for one of these disorders. Current research supports a genetic basis for ASDs. Although a link between vaccinations and ASDs has received recent media attention, current research strongly supports the likelihood that ASDs are not caused by vaccinations.

What are the symptoms of ASDs?

There are three categories of symptoms of ASDs

1. Impairments in Social Interaction

Children with ASDs may withdraw from others and may not seek attention or actively engage with other children or adults. They can demonstrate difficulties with joint attention (sharing interest) and may not follow or initiate pointing to show interest in something. They may not orient to social stimuli (not turning to respond to hearing their name). Research has suggested that children with ASDs may lack *Theory-of-Mind,* which is the understanding that others have thoughts, desires, and beliefs which differ from one's own, as required in being able to consider something from the perspective of another.

2. Impairments in Communication

Children with ASDs have difficulties in both verbal and non-verbal communication, ranging from a complete absence of spoken language to odd or idiosyncratic language. These children's unconventional communicative behaviours may include language that seems robotic or scripted from television, repetitive or echolalic language (parroting), and "pop-up" and / or "giant" words (such as "whatisthis"). Delayed onset of speech is common.

3. Restricted, Repetitive and Stereotyped patterns of Behaviours, Interests and Activities

Children with ASDs may demonstrate highly specific and focused interests (e.g., obsessions with maps or sea creatures) to the exclusion of other interests. They may also demonstrate inflexibility with regard to routines (e.g., perseveration on using a particular route), and stereotyped mannerisms (e.g., hand-flapping, self-injurious behaviours). These symptoms may emerge later than the others due to early limitations in physical development.

For video examples of symptoms associated with ASDs, see the Video Glossary at Autism Speaks: http://www.autismspeaks.org/video/glossary.php

How can Physicians Conduct Surveillance for ASDs in their Regular Practice?

Surveillance is the continuous process of monitoring child development, requiring knowledge of typical developmental milestones and, in specific reference to ASDs, an understanding of the symptoms of ASDs and their patterns of emergence. As one of the primary professional contacts for parents, it is important that physicians stay alert for any signs and symptoms suggestive of ASDs.

1. Listen to parents when they express concerns about their child. The concerns of worried parents often have a valid basis.
2. If parents don't mention any worries, ask them directly if they have any concerns about their child.
3. Ask about family history of ASDs or other developmental delays. Children with a sibling or other first degree relative with an ASD are at increased risk.
4. Note the child's failure to meet the following developmental milestones.

   N.B. A single missed milestone may not be cause for concern (unless it is loss of language), but pay particular attention when more than one of the following milestones has not been met:

   - Diminished, atypical, or no babbling by 12 months
   - Diminished, atypical, or no gesturing (e.g., pointing, waving bye-bye) by 12 months
   - Lack of response to name by 12 months
   - No single words by 16 months
   - Diminished, atypical, or no two-word spontaneous phrases (excluding echolalia or repetitive speech) by 24 months
   - Loss of any language or social skill at any age
   - Lack of joint attention
5. Engage the child in activities that may alert you to delays:
   - Point at something interesting. A child with an ASD may not follow your point at all, or may look at your finger instead.
   - Call the child's name. A child with an ASD may not orient to you.
   - Engage the child in conversation about a topic of interest. Look for any delays in speech, oddities in use of language, or intense focus on a topic of interest, to the exception of any other topic.

What if an ASD is suspected?

If either you or the child's parent suspects an ASD or other developmental delay, or if there is a family history of ASDs, a formal ASD screen should be conducted. This means that a standardized screening tool should be administered, immediately.

Do Not "Wait and See"

The Canadian Pediatric Society (2004) provides evidence that intensive behavioural interventions, provided early in life, lead to positive outcomes for children with ASDs. The earlier these interventions are initiated, the better the outcomes, especially for children whose symptoms may be more mild and less easily noticed by parents or professionals. It is critical that children with ASDs be identified as early as possible, so that they can begin to benefit from effective behavioural interventions.

How do physicians formally screen for ASDs?

Targeted screening involves using a standardized screening tool to measure risk for ASDs in children who are considered to be particularly at-risk for the disorder, including children who have been identified by professionals due to missed milestones or the presence of ASD symptoms, children whose parents have expressed concerns, and children with a sibling with an ASD or other developmental delay.

The Modified Checklist for Autism in Toddlers The Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, Barton & Green, 2001) is a short questionnaire that may be given to parents of children between 16 and 30 months of age to complete in the waiting room. A follow-up interview may be used to decrease the false positive rate. The M-CHAT and follow-up interview may be obtained for free at:

- http://www2.gsu.edu/~wwwpsy/faculty/robins.htm.

The Checklist for Autism in Toddlers (CHAT; Baron-Cohen et al., 1996), which incorporates direct behavioural observation, can also be used by physicians with training and experience in ASDs.

To obtain permission to use the CHAT for professional, scientific or clinical purposes:

- http://www.autismresearchcentre.com/tests/chat_test.asp

The Screening Tool for Autism in Two-Year Olds (STAT; Stone & Ousley, 1997) can be used by physicians specifically trained in its administration to distinguish ASDs from other developmental delays in children aged 24-36 months. To obtain information about the STAT:

- http://kc.vanderbilt.edu/kennedy/triad/services_screening.html

What if a child's screening results are positive?

If the child scores above the cut-off for the screening test, indicating a positive screening result, it indicates that the child is at high-risk for a diagnosis of ASDs. It does not mean that the child can be diagnosed with an ASD. The following actions are recommended:

1. Refer the child to an interdisciplinary diagnostic team for a full ASD assessment OR refer the child to an expert diagnostician with specific training and experience in ASDs.
2. Refer the child for an audiology assessment to rule out a hearing disability and a Speech-Language Pathologist to rule out other communication disorders, unless these specialists are members of the interdisciplinary assessment team.
3. Offer parents the "Parent's Guide to Screening and Diagnosis of ASDs in Very Young Children," which includes the following list of websites with accurate and reliable information on ASDs:

- Autism Central: www.autismcentral.ca
- Autism Connects: http://www.autismconnects.ca
- Autism Society of Canada: http://www.autismsocietycanada.ca
- Canadian Autism Intervention Network: www.cairn-site.com
- Health Canada's Autism website: http://www.hc-sc.gc.ca/dc-ma/autism/index_e.html

What is involved in an ASD diagnosis?

1. The clinical diagnosis must be in accordance with Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) and / or International Classification of Diseases (ICD-10) diagnostic criteria.
2. The diagnosis of ASDs in young children should only be made by a psychologist or a physician under the conditions that they are:
    - Members of a professional order or college that permits the transmission of diagnoses
    - Have graduate (doctoral level) or post-graduate training encompassing specific training in child development and ASDs and other developmental disorders in young children.
    - Have received supervised clinical experience in the assessment and diagnosis of ASDs in young children.
3. It is highly recommended that ASD diagnoses be made within the context of a interdisciplinary team assessment; however, solitary practitioners can diagnose ASDs in consultation with other professionals.
4. The diagnosis of ASDs requires a detailed developmental history, a parent interview, and direct behavioural observation. Many diagnosticians are trained to use the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview-Revised (ADI-R), which are standardized diagnostic tools.
5. The assessment of cognitive and developmental level is central to the diagnosis of ASDs, as children with autistic disorder may have co-morbid intellectual disabilities.
6. A process of differential diagnosis must be undertaken to ensure a comprehensive diagnostic formulation and to rule out other possible causes for the symptoms.

M-CHAT

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/~wwwpsy/faculty/robins.htm

Users should be aware that the M-CHAT continues to be studied, and may be revised in the future. Any revisions will be posted to the two websites noted above.

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

The M-CHAT is validated 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 was 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, we have 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.

The M-CHAT can be scored in less than two minutes. Scoring instructions can be downloaded from http://www2.gsu.edu/~wwwpsy/faculty/robins.htm or www.firstsigns.org. We also have developed a scoring template, which is available on these websites; when printed on an overhead transparency and laid over the completed M-CHAT, it facilitates scoring. Please note that minor differences in printers may cause your scoring template not to line up exactly with the printed M-CHAT.

Children who fail more than 3 items total or 2 critical items (particularly if these scores remain elevated after the follow-up interview) should be referred for diagnostic evaluation by a specialist trained to evaluate ASD in very young children. In addition, children for whom there are physician, parent, or other professional's concerns about ASD should be referred for evaluation, given that it is unlikely for any screening instrument to have 100% sensitivity.

M-CHAT Scoring Instructions

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. Not all children who fail the checklist will meet criteria for a diagnosis on the autism spectrum. However, children who fail the checklist should be evaluated in more depth by the physician or referred for a developmental evaluation with a specialist.

1	No	6	No	11	Yes	16	No	21	No
2	**NO**	**7**	**NO**	12	No	17	No	22	Yes
3	No	8	No	**13**	**NO**	18	Yes	23	No
4	No	**9**	**NO**	**14**	**NO**	19	No		
5	No	10	No	**15**	**NO**	20	Yes		

Modified Checklist for Autism in Toddlers (M-CHAT)*

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* The full text may be obtained through the Journal of Autism and Developmental Disorders, April 2001

PLEASE NOTE: The M-CHAT was not designed to be scored by the person taking it. In the validation sample, the authors of the M-CHAT scored all checklists. If parents are concerned, they should contact their child's physician.

Abstract

Autism, a severe disorder of development, is difficult to detect in very young children. However, children who receive early intervention have improved long-term prognoses. The Modified Checklist for Autism in Toddlers (M-CHAT), consisting of 23 yes/no items, was used to screen 1,293 children. Of the 58 children given a diagnostic/ developmental evaluation, 39 were diagnosed with a disorder on the autism spectrum. Six items pertaining to social relatedness and communication were found to have the best discriminability between children diagnosed with and without autism/PDD. Cutoff scores were created for the best items and the total checklist. Results indicate that the M-CHAT is a promising instrument for the early detection of autism.

Background

The M-CHAT is an expanded American version of the original CHAT from the U.K (Baron-Cohen et al., 1992; 1996). The M-CHAT has 23 questions using the original nine from the CHAT as its basis. The goal of the ongoing M-CHAT research is to demonstrate adequate psychometric properties of the M-CHAT (sensitivity, specificity, positive and negative predictive power). The M-CHAT is available for clinical and research use, with the following caveats:

1. Clinical use should proceed with caution, given that the current scoring system is designed to maximize sensitivity (i.e., identify as many children with autism spectrum disorders as possible), which results in a number of false positive cases (i.e., children who will not be diagnosed with an autism spectrum disorder, although they fail the M-CHAT). Once cross-validation of the M-CHAT is complete, the scoring may be revised.

2. The M-CHAT is not designed to detect all possible developmental disorders. Any parents who have concerns about their child should see their child's physician, regardless on the child's score on the M-CHAT. M-CHAT research is ongoing at the University of Connecticut and Georgia State University. The follow-up study of the initial sample is expected to be published in the near future. This research is supported by funding from the National Institute of Child Health and Development, the Maternal and Child Health Bureau, and the National Alliance for Autism Research. For more information, please contact Diana Robins at drobins@gsu.edu or Deborah Fein at Deborah.fein@uconn.edu.

M-CHAT

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've 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 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

Contact Us

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For free downloads of this document, as well as a Best Practice Guidelines, waiting room poster, and Parent Guide to Screening, Assessment and Diagnosis of ASDs, please visit www.autismcentral.ca.

To inquire about ordering multiple copies of the Best Practice Guidelines, Physician Toolkit, waiting room poster, and Parent Guide to Screening, Assessment and Diagnosis of ASDs, please call the Miriam Foundation at **(514) 345-1300** or email bestpractices@miriamfoundation.ca.

Please contact Jennifer Nachshen at **(514) 345-1300 x 368** or jennifern@miriamfoundation.ca, if you have any questions, comments, or concerns.

ABOUT THIS TOOLKIT

The Physician Toolkit and Best Practices Handbook seek to establish consistency in the processes used to diagnose Autism Spectrum Disorders by developing standardized Canadian best practices for screening and early diagnosis of individuals with Autism Spectrum Disorders.

The toolkit was published by the Miriam Foundation. Established in 1970, the Foundation is a not-for profit foundation which supports rehabilitative, vocational and residential services for children and adults living with intellectual disabilities or autism spectrum disorders.