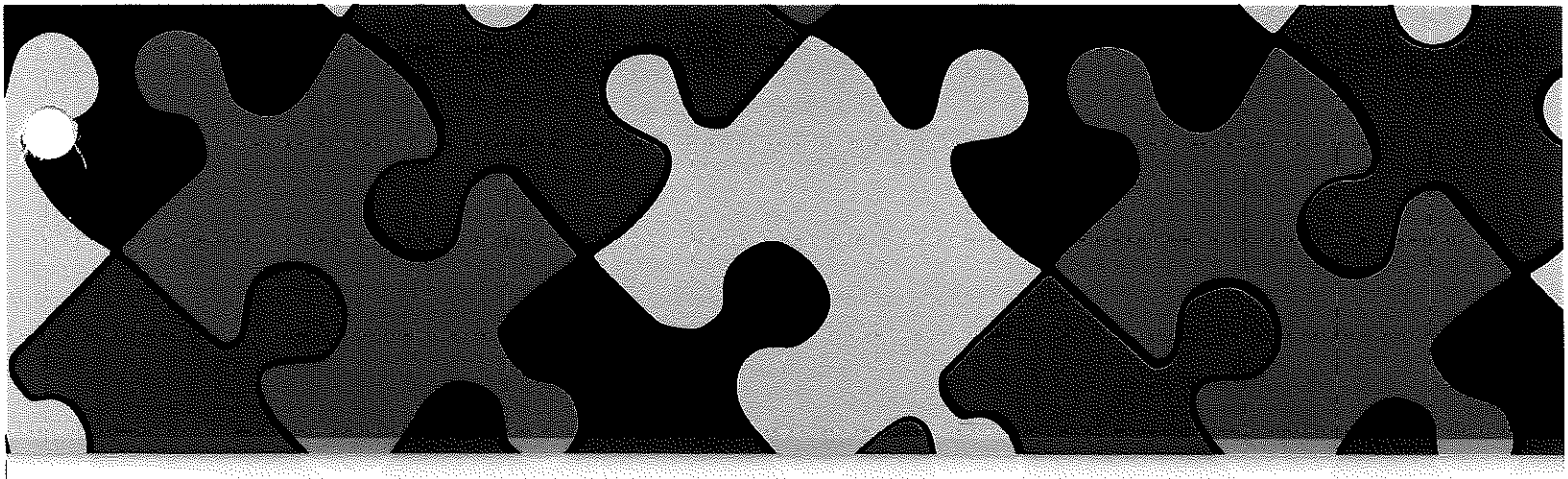
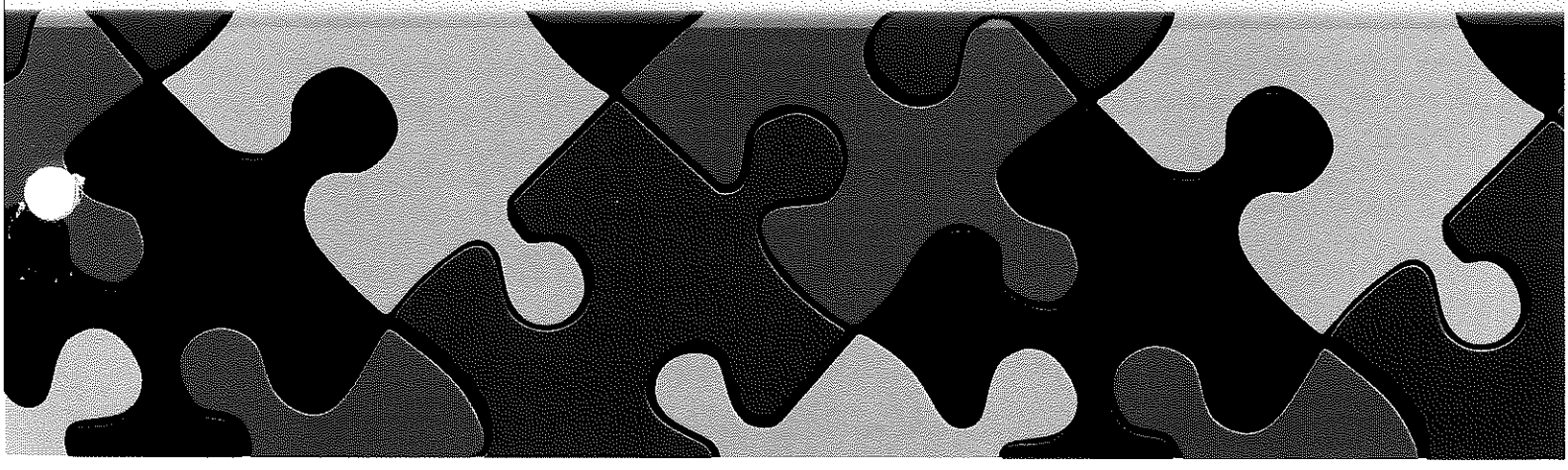


NEW YORK STATE DEPARTMENT OF HEALTH
BUREAU OF EARLY INTERVENTION

JULY, 2013

Best Practice Protocol for Early Screening of Young Children for Autism Spectrum Disorders (ASDs) by Pediatric Primary Care Providers



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Introduction

Section 2500-J of the New York State Public Health Law requires the Commissioner of Health to establish best practice protocols for early screening of young children for autism spectrum disorders (ASD). The best practice protocols must incorporate standards and guidelines issued by the American Academy of Pediatrics (AAP), and include:

- The routine employment of objective ASD screening tools at regular intervals during critical childhood developmental stages.
- A provider/parent dialogue, using the Modified Checklist for Autism in Toddlers as a reference, to educate parents about ASD.
- An appropriate referral mechanism for children who, based on the results of the screening process, require further evaluation.

This ***Best Practice Protocol for Early Screening of Young Children for Autism Spectrum Disorders by Pediatric Primary Care Providers*** is being issued in fulfillment of this requirement. In addition to the standards and guidelines issued by the AAP, the *Best Practice Protocol* incorporates a subset of the evidence-based recommendations for early identification and assessment of young children for autism/pervasive developmental disorders included in the New York State Department of Health's (NYSDOH) clinical practice guideline, *Autism/Pervasive Developmental Disorders: Assessment and Intervention for Young Children (Age 0-3).*

The NYSDOH clinical practice guideline on autism/pervasive developmental disorders in young children was developed using the methodology for guideline development established by the Agency for Health Care Research and Quality.[1]

For additional information or to order the NYSDOH clinical practice guidelines please visit:

http://www.health.ny.gov/community/infants_children/early_intervention/disorders/autism/

[1] Issued in 1999, the NYSDOH guideline was the first evidence-based guideline addressing assessment and intervention for young children with autism. The guideline is being updated by the Department with support from the FAR Fund and will be reissued in 2014 to reflect scientific evidence which has emerged since that time. In preparing this protocol, the Department consulted with physician experts who determined the guideline recommendations on early identification of children with ASDs continue to be useful and important for pediatric practices. Future editions of this best practice protocol will be revised to incorporate new or revised recommendations resulting from the guideline update.

Autism Portal for Physicians

The NYSDOH Bureau of Early Intervention has developed an online resource for locating services and guidance for children with ASD for pediatricians and family medicine practices to help their patients and families. This is a membership only site for physicians and their medical practices.

Key features of the portal include:

- Access local, state and federal resources related to ASD
- Access information on screening tools
- Make a referral to the Early Intervention Program
- Request resources, ask questions, and start or join discussions among colleagues on the Physicians Forum
- Find trainings and meetings listed on the Calendar of Events
- Download resources related to ASD

Membership:

To become a member of the *Autism Portal for Physicians* or for additional information, please contact:

New York State Department of Health
Bureau of Early Intervention
(518)473-7016
bei@health.state.ny.us

Symbols

The following symbols are used to denote recommendations from:

AAP

NYSDOH clinical practice guidelines, *Autism/Pervasive Developmental Disorders: Assessment and Intervention for Young Children (Age 0-3)*

What Are Autism Spectrum Disorders?

ASDs represent three of the pervasive developmental disorders defined in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) and DSM-IV-TR (text revision): autistic disorder, pervasive developmental disorder-not otherwise specified, and Asperger syndrome. [2]

ASDs are severe disorders of development that affect social relatedness, communication, play, and adaptive functioning. During the past decade, there has been growing national awareness and concern about the increasing prevalence of ASDs among young children.

Approximately 1 in 88 children meet the diagnostic criteria for one of these disorders. Current research suggests 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. [3] [4]

There is now clear evidence to demonstrate that ASDs can be identified and reliably diagnosed as early as 18 months of age.

Early identification and treatment of ASDs can lead to lifelong improvement in health, development, and functioning for children and youth with ASD, especially when early services are followed by effective transition to coordinated health, mental health, educational, and community supports.

[2] Plauché Johnson, C., Myers, S.M., and the Council on Children with Disabilities. (2007). Identification and Evaluation of Children with Autism Spectrum Disorders. Pediatrics, Volume 120:5.

[3] Miriam Foundation, 2008. Surveillance and Screening for Autism Spectrum Disorders in Very Young Children PHYSICIAN TOOLKIT. Based on the Canadian Best Practice Guidelines, Miriam Foundation.

[4] Centers for Disease Control. Prevalence of Autism Spectrum Disorders: Autism and Developmental Disabilities Monitoring, Network 14 Sites, United States, 2008. Morbidity and Mortality Weekly Report: Surveillance Summaries, Volume 61, No. 3, March 30, 2012.

What are the symptoms of ASDs?

Recognition of symptoms of autism occurs *within the first three years of life.*

There are three categories of symptoms of ASDs:

1. Impairments in Social Interactions

   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 behaviors 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 Behaviors, 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., preservation on using a particular route), and stereotyped mannerisms (e.g., hand-flapping, self-injurious behaviors). These symptoms may emerge later than others due to early limitations in physical development at this young age. [5]

The DSM-IV Diagnostic Criteria for autistic disorder is the gold standard for diagnosing autism spectrum disorders. These diagnostic criteria are included in Tables 1-3, Appendix A.

The DSM-5 is the fifth edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders*. It was published in May 2013 and supersedes the DSM-IV.

For information about the changes to DSM-5 from DSM-IV, please go to www.dsm5.org

[5] Adapted from: Surveillance and Screening for Autism Spectrum Disorders in Very Young Children: Physician Toolkit. Based on the Canadian Best Practice Guidelines. Miriam Foundation 2008.

General Approach to Early Identification of Young Children with Autism

Importance of Early Identification of Autism

It is important to identify children with autism and begin appropriate interventions as soon as possible since early intervention may help speed the child's overall development, reduce inappropriate behaviors, and lead to better long-term functional outcomes. It is often possible to recognize autism within the first three years of life.

Early identification of autism allows for:

- early intervention
- etiologic investigation - (A history and thorough physical by a knowledgeable clinician to evaluate for comorbid conditions and specific causes of ASDs, e.g. tuberous sclerosis, PTEN mutation, and others)
- counseling regarding recurrence risk [6]

Identifying Initial Concerns about Possible Autism

It is important for professionals, including child care providers, and parents to recognize that there are several ways that children with autism are first identified. These ways include:

- a parent or professional's concern that some aspect of the child's development is delayed or something is abnormal about the child's behavior
- a health care provider's or other professional's concern about possible autism either at the time of a periodic health exam, or when the child is being evaluated for some other health problem (such as a possible hearing loss) or developmental problem (such as a delay in talking or does not talk, does not make eye contact)

Developmental Surveillance

Developmental surveillance is a flexible, continuous process in which knowledgeable professionals monitor a child's developmental status during the provision of health care services.

[6] Plauché Johnson, C., Myers, S.M., and the Council on Children with Disabilities. (2007). Identification and Evaluation of Children with Autism Spectrum Disorders. Pediatrics, Volume 120:5.

General Principles of Developmental Surveillance for Young Children

Developmental surveillance done routinely at specific ages is important for all young children. Health care providers can provide such surveillance and can facilitate the identification of developmental problems as early as possible.

Importance and Timing of Developmental Surveillance

- Given the fact that the Centers for Disease Control and Prevention (CDC) estimates that an average of 1 in 88 children in the United States has an ASD, primary care providers are likely to provide care for children with ASD. [7]
- Periodic developmental surveillance by appropriately trained and qualified health care providers or other professionals is important for all young children. Such routine surveillance provides an active way to identify developmental problems as early as possible.
- Periodic health examinations provide specific opportunities for routine developmental surveillance in young children. During these exams, parent reports about their child's behaviors and direct observations of the child by the examiner may provide useful clues to help identify concerns about possible developmental problems, including ASD.
- The periodic exams at **15, 18, and 24** months are particularly useful in providing information about possible autism, since characteristics of autism often begin to emerge during the second year of life. During these exams, it is particularly important to assess social development as well as motor and language development.
- **Developmental surveillance should begin at birth and occur at every preventive visit throughout childhood.** [8]

Components of Developmental Surveillance

It is recommended that developmental surveillance for young children include the following components:

- eliciting and attending to parents' concerns
- obtaining and maintaining a relevant developmental history
- making informed and accurate observations of the child
- sharing opinions and concerns with parents and other professionals who care for the child
- identifying the presence of risk and protective factors
- documenting the process and findings [9]

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[7] Cited from http://www.cdc.gov/ncbddd/autism/index.html, accessed on January 4, 2011.

[8] Plauché Johnson, C., Myers, S.M., and the Council on Children with Disabilities. (2007). Identification and Evaluation of Children with Autism Spectrum Disorders. Pediatrics, Volume 120:5.

[9] Op. Cit.

General Principles of Developmental Surveillance for Young Children

Developmental Screening [10]

All children, most of whom will not have identifiable risks or whose development appears to be proceeding typically, should receive periodic developmental screening using a standardized test.

In the absence of established risk factors or parental or provider concerns, a general developmental screen is recommended at the 9, 18, and 30 month visit.

- Because the 30 month visit is not yet part of the preventive care system, developmental screening can be performed at 24 months of age.
- The frequency of regular pediatric visits decreases after 24 months of age. A pediatrician who expects that his or her patients will have difficulty attending the 30 month visit should conduct the screening during the 24 month visit.

If screening results are concerning, the child should be scheduled for developmental or medical evaluations.

[10] These recommendations are statements directly excerpted from: American Academy of Pediatrics, Council on Children with Disabilities, Section on Developmental Pediatrics, Bright Futures Steering Committee and Medical Home Initiatives for Children with Special Health Care Needs Project Advisory Committee. *Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening.* Pediatrics, 2006; 118; 405 DOI: 10.1542.2006-1231.

Assessing Developmental Milestones that are Relevant to Autism

One method of developmental surveillance is for the professional to look for certain age-specific developmental milestones. Siegel (1991) has provided a useful series of tables on the normal developmental milestones in the social and communicative behavior domains that are pertinent to autism. This information from Siegel, along with other information about clinical clues in articles reviewed by the NYSDOH consensus panel on autism/pervasive developmental disorders in young children, was used to identify the following *Developmental Milestones for Communication and Social Skills.* [11]

These developmental milestones are solely to be used to inform the pediatrician's clinical impression of a child's behavior and should not be abstracted and used as a screening tool.

Developmental Milestones for Communication and Social Skills

These are developmental milestones that children following a typical developmental sequence should exhibit by the time they reach the specified age. Failure to achieve a developmental milestone is a clinical clue that raises concerns that the child may have autism or some other developmental delay or disorder.

15 month developmental milestones

- Makes eye contact when spoken to
- Reaches to anticipate being picked up
- Shows joint attention (shared interest in object or activity)
- Displays social imitation (such as a reciprocal smile)
- Waves "bye-bye"
- Responds to spoken name consistently
- Responds to simple verbal request
- Says "Mama," "Dada," specific

18 month developmental milestones *(All of the above, plus the following)*

- Points to body parts
- Speaks some words
- Has pretend play (such as symbolic play with doll or telephone)
- Points out objects
- Responds when examiner points out object

24 month developmental milestones *(All of the above, plus the following)*

- Uses two-word phrases
- Imitates household work
- Shows interest in other children

[11] Adapted from Siegel, 1991, and Table III-5, Evidence-based Clinical Clues of Possible Autism, New York State Department of Health, Early Intervention Program, 1999. Report of the Recommendations: *Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3 Years)*, pp 58-60. See Appendix B of this protocol for this table.

Assessing Developmental Milestones that are Relevant to Autism

Identifying Clinical Clues of Possible Autism

A small number of easily observed behaviors can be considered "clinical clues" that heighten the concern about possible autism in a child. Clinical clues of possible autism may be identified by parents, healthcare providers, or other professionals who interact with the child.

It is recommended that certain inappropriate behaviors or the lack of certain age-appropriate behaviors be considered as clinical clues for possible autism. These clinical clues signal a need for further evaluation of possible autism.

The clinical clues represent delayed or abnormal behaviors that are often seen in young children with autism beginning in the second year of life. Some of these findings may also be seen in children who do not have autism but who may have other developmental problems.

Clinical Clues for Possible Autism [12]

- Delay or absence of spoken language
- Looks through people; not aware of others
- Not responsive to other people's facial expressions/feelings
- Lack of pretend play; little or no imagination
- Does not show typical interest in, or play near peers purposefully
- Lack of turn taking
- Unable to share pleasure
- Qualitative impairment in nonverbal communication
- Not pointing at an object to direct another person to look at it
- Lack of gaze monitoring
- Lack of initiation of activity or social play
- Unusual or repetitive hand and finger mannerisms
- Unusual reactions, or lack of reaction, to sensory stimuli

If any of these clinical clues are present in a toddler, further assessment may be needed to evaluate the possibility of autism or other developmental problems.

[12] Adapted from Table III-5, Evidence-based Clinical Clues of Possible Autism, New York State Department of Health, Early Intervention Program, 1999. *Report of the Recommendations: Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3 Years)*, pp 58-60. See Appendix B of this protocol for this table.

Assessing Developmental Milestones that are Relevant to Autism

How can Physicians Conduct Screening and Surveillance for ASDs in their Regular Practice? [13]

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 ASD.

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 milestones. *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 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 of language, or intense focus on a topic of interest, to the exception of any other topic.

[13] Adapted from Physician Toolkit: Surveillance and Screening for Autism Spectrum Disorders in Very Young Children. Based on the Canadian Best Practice Guidelines, Miriam Foundation, 2008.

Synopsis of the American Academy of Pediatrics (AAP) - Surveillance and Screening Algorithm for ASDs

Note: The complete algorithm is reprinted in Appendix C.

STEP 1 [14] Surveillance at the first preventive care visit should begin with a **family history** to determine if there are any family members, especially siblings, who have been diagnosed with ASD.

- The risk of having symptoms of ASD in younger siblings of children with ASD is approximately 10 times higher.
- Primary health care providers need to be extra vigilant in monitoring these children for early abnormal signs.

Very early signs of ASD in infants reported by investigators include:

- Extremes of temperament and behavior (ranging from marked irritability to alarming passivity)
- Poor eye contact
- Poor response to others' voices, especially to one's name being called
- Poor attempts at interactive play
- More interest in looking at objects than at people
- Decreased to and fro babbling and jargoning
- Lack of warm, joyful reciprocating expressions (p 1195)

STEP 2 Surveillance should include asking parents open-ended questions about their concerns regarding their child's development and behavior.

- The AAP patient education brochure, *"Is Your One-Year-Old Communicating With You?"* can be distributed to all parents at their child's 9-or-12 month preventive visit to educate them about early social communication milestones to help them identify valid concerns.
- Asking age specific questions about whether certain developmental milestones have been attained can help guide the discussion with parents.
- Ask about the development of verbal and nonverbal communication, reciprocal social interaction, and representational or pretend play skills.
- The American Child Neurology Society practice parameter on screening and diagnosis for autism suggests the following "red" flags are absolute indications for immediate evaluation:
  - No babbling or pointing or other gesture by 12 months
  - No single words by 16 months
  - No 2-word spontaneous (non-echolalic) phrases by 24 months
  - Loss of language or social skills at any age (p. 1198)

[14] Plauché Johnson, C., Myers, S.M., and the Council on Children with Disabilities. (2007). Identification and Evaluation of Children with Autism Spectrum Disorders. Pediatrics, Volume 120:5.

Synopsis of the American Academy of Pediatrics (AAP) - Surveillance and Screening Algorithm for ASDs

Pediatricians should become concerned if parent responses to these questions reveal deficits or delays in milestones or if behaviors typical of ASD are observed during an office visit.

Each concern raised by a parent, caregiver, or the pediatrician constitutes a separate risk factor, as does a positive family history of a sibling with ASD.

STEP 3 To determine how to proceed, the pediatrician should assess the number of risk factors. Possible scores include 0, 1, 2, 3, or 4.

1. If no concerns have been raised during the course of the preventive visit and the child is not the sibling of a child with ASD, the primary care provider (PCP) should proceed to **AAP Step 4**. ASD-specific screening is indicated only if the visit is the 18- or 24-month preventive visit.
2. If the child's only risk factor is having a sibling with ASD, the PCP should make sure the parent is aware of early signs of ASD and continue to monitor carefully. If the parents call with a concern between routine preventive visits, the child should be seen within 1-2 weeks and re-enter the algorithm at Step 1b for a "targeted visit" to address concerns about ASDs. If the score = 1 as the result of a single concern by anyone, the PCP should screen the child formally with a standardized tool; the choice of tool will depend on the child's age.
3. If 2 or more risk factors are identified, then the PCP should proceed directly to Step 8, which includes several activities that should be accomplished simultaneously and without delay.

It is important that pediatricians and other child health practitioners are able to recognize the signs and symptoms of ASDs and have a strategy for assessing them systematically.

It is critical that PCPs be aware of new data that support better outcomes in children whose conditions are diagnosed early and participate in appropriate intervention programs.

STEP 4 In the absence of established risk factors and parental/provider concerns (score=0), **an ASD-specific tool should be administered at the 18- and 24-month visits.**

- A general developmental screening using a standardized instrument is recommended for all children at the 9-, 18-, and 24- or 30-month visits. [15]

STEP 5 Screening for Autism Spectrum Disorders.

Step 5a and b. A standardized screening tool should be administered at any point when concerns about ASD are raised by a parent or as a result of clinician observations or surveillance questions about social, communicative, and play behaviors. Physician estimates of the developmental status of children are much less accurate when only clinical impressions are used, compared with the use of formal developmental screening instruments.

[15] American Academy of Pediatrics Policy, Identifying Infants and Young Children with Developmental Disorders in the Medical Home.

- For children younger than 18 months of age, the pediatrician should use a tool that specifically addresses the clinical characteristics of ASD, such as those that target social-communication skills.
- For children 18 months and older, the pediatrician should use an ASD-specific screening tool.

Step 5c. A standardized ASD specific screening tool should be administered for ALL children at the 18-month preventive care visit.

- A repeat, standardized ASD specific screening should be performed for ALL children at 24 months of age to identify those who may regress after 18 months of age.

Screening Tools for Step 5

A variety of developmental screening tools are available for use by pediatric care providers. General developmental tools are appropriate for use with unselected primary care populations and are likely to detect ASDs in many young children.

- General developmental screening tools do not differentiate children with ASDs from those with other developmental disorders.
- Tools to screen for ASD have been designed but have not yet been validated for children younger than 18 months of age.
- Screening tools are likely to be over inclusive, so children with developmental and behavioral disorders other than ASD also might have positive screening results.

Screening Tools for Step 5a – Tools for Use in "at-risk" children younger than 18 months

The Infant/Toddler Checklist from the Communication and Symbolic Behavior Scales Developmental Profile may be particularly well-suited for 12- to 24-month-old children who are at risk of ASDs, because it focuses on social and communication skills.

- The Infant and Toddler Checklist may be useful for children younger than 12 months; however, data are not yet available which document its use with infants less than 12 months of age.

Screening Tools for Step 5b – Tools for Use in "at-risk" children 18 months and Older

ASD-specific screening tools are available for children 18 months and older. Many of these tools are age-specific. "Level 1" screening tools are tools that are administered to all children by primary care providers. Level 1 screening tools are used to differentiate children at risk of ASDs from the general population, especially children with typical development.

- The Checklist for Autism in Toddlers and Modified Checklist for Autism in Toddlers (M-CHAT) are level 1 screening tools that are available at no cost to the practitioner for use in primary care settings.

- The M-CHAT and M-CHAT follow-up parent interview is a two-step screening tool meant to be given by primary health care providers to identify a child's risk for an ASD (See Appendix D for the M-CHAT). The M-CHAT screen and follow-up interview, instructions, and supplemental materials are available for free download at **www.mchatscreen.com**.
- The M-CHAT screen and follow-up parent interview can be used to screen toddlers between 16 and 30 months of age. The M-CHAT consists of 23 yes/no questions that parents answer about their child's behavior and development. It can be given and scored by a health care provider as part of a well-child checkup. For children whose scores on the M-CHAT show that they are at risk for ASDs, the M-CHAT follow-up parent interview should be given also by the provider. The interview can be completed in 5-15 minutes. The M-CHAT is simple to use and can be given by a provider with little training in ASDs.

When using the M-CHAT, it is important to note the following:

- The M-CHAT is not intended to be used by parents to screen their own children.
- Giving the paper and pencil M-CHAT screen without giving the follow-up interview is not recommended at this time. Results may not be accurate when the follow-up interview is not used.
- The M-CHAT and follow-up parent interview is a screening tool. It is not to be used to make a formal or specific ASD diagnosis.
- Not all children shown to be at risk for an ASD based on the M-CHAT and follow-up interview will be diagnosed with an ASD. However, the screening tool can also identify children who are at risk for other developmental delays or disorders that require intervention.

"Level 2" screening tools are used in early intervention programs or developmental clinics, to differentiate children at risk of ASDs from those at risk for other developmental disabilities.

- There is overlap between the concept of a level 2 screening tool and that of a diagnostic instrument.
- Level 2 screening tools may be used as part of a diagnostic evaluation, but they should not be used in isolation to make a diagnosis.

Screening Tools for Step 5b – Tools for screening children without risk factors at the 18- and 24-month preventive visit

Level 1 ASD tools described in Step 5b are also appropriate for routine screening of young children without any identified risk for autism.

See Appendix E, Selected Level 1 and 2 ASD Screening Measures (AAP, 2007, pp 1200-1201)

STEP 6 Determine the results of the screening.

Step 6a. When the screening result for an at-risk child is negative, the pediatrician should go to **Step 7a**.

Step 6b. When the screening result for children without risk is negative at the 18- or 24 month preventive visit, the pediatrician should go to **Step 7b**.

Synopsis of the American Academy of Pediatrics (AAP) - Surveillance and Screening Algorithm for ASDs

STEP 7 Provide the parents with information.

Step 7a. When a screening result is negative for an at-risk child, the pediatrician should do the following:

- Provide the parent with educational materials (such as the AAP brochure, *Is your one-year old communicating with you?* or the AAP brochure *Understanding Autism Spectrum Disorders*, or the NYS Department of Health Brochure, *Autism: Early Help Makes a Difference* brochure).
- Schedule a visit within 1 month to address residual concerns.
- If the only risk factor is having a sibling with an ASD, an extra visit is not necessary unless parents are continuing to express concern about their child's development or autism.
- Re-enter the child into the algorithm at **Step 1b**.

Step 7b. When a screening result is negative at the 18- or 24-month preventive visit, the pediatrician should do the following:

- Schedule the next routine preventive care visit.
- Continue to include developmental concerns, including those about social skills deficits, as one of several topics addressed at each pediatric preventive care visit through the first five years of life.
- Re-enter the child into the algorithm at **Step 1a**.

STEP 8 If the results of screening are positive or concerning, "do not wait and see". Take immediate action to inform parents and assist them in obtaining further evaluation for their child and a referral for early intervention services – **Step 8.2.b**.

Step 8.1. If the primary care provider is fairly certain that the child has a developmental disorder that falls somewhere on the autism spectrum, it will be helpful to give the parents reading materials.

- The AAP educational booklet for parents, *Understanding Autism spectrum Disorders*, is a useful resource for parents.
- The evaluation process will progress more efficiently if parents are more knowledgeable about the characteristic clinical symptoms of ASDs, and can report them accurately.
- When discussing possible autism with parents, sincerity, honesty and admitting uncertainty is appreciated by most parents.

Synopsis of the American Academy of Pediatrics (AAP) - Surveillance and Screening Algorithm for ASDs

Step 8.2a. Need for further evaluation based on developmental findings

- When a health care provider suspects that a child may have autism, further evaluation is recommended. Such evaluations might occur either through private consultants (paid for by private health insurance or directly by the family) or through a publicly funded early intervention program.
- Ideally, the definitive diagnosis of an ASD should be made by a team of child specialists with expertise in ASD.
- If it seems fairly certain, on the basis of general developmental screening and/or available psychometric testing with standardized tools, that the child also has global developmental delays or intellectual disabilities, the PCP could consider ordering chromosomal microarray testing and DNA testing for fragile X syndrome.
- Girls with regression in language and motor milestones prior to the emergence of the hand stereotypy should be considered for MeCP2 testing.
- If the child has clinical features (history, family history, physical examination) that are characteristic of a specific genetic or neurologic disorder, then the PCP may want to order the appropriate test.
- The PCP may opt to refer the child to pediatric subspecialists for assistance with an etiologic workup or a search for co-existing conditions.

Step 8.2.b. Referral to Early Intervention/Early Childhood Education Services

- As soon as an infant or toddler under the age of three is suspected of having a delay or developmental disorder such as ASD, she/he should be referred immediately to the public Early Intervention Program in his or her county of residence (see Appendix F for a list of municipal Early Intervention Programs and a sample referral form).
- If the child will turn three years of age within forty-five days of identifying developmental concerns, including ASD, or has already turned three years of age, the child should be referred to the committee on preschool special education in his or her school district.

Step 8.2.c. Audiology Evaluation

- All children with language delays, including those suspected of having ASDs, should undergo an audiologic evaluation, even if the neonatal screening result was normal.

Step 8.3 and 8.4. Schedule Follow-up Visit and Reenter Algorithm

- The child should be scheduled for a targeted follow-up visit within 1 month and re-enter the algorithm at Step 1b to determine the status of referrals and to discuss any additional parental concerns once they have had the opportunity to read and learn more about ASDs.

Diagnostic Challenges and Recommendations for Comprehensive Assessment

There are three major diagnostic challenges in the comprehensive assessment of a child with suspected ASD: [16]

1. Determining the child's overall level of functioning
2. Making the categorical diagnosis of an ASD
3. Determining the extent of the search for an associated etiology.

To accomplish these 3 goals, a comprehensive evaluation should have the following components:

1. Health, developmental, and behavioral histories that include at least a 3-generation family pedigree and a review of systems.
2. Physical examination, including a thorough search for dysmorphic features and neurologic abnormalities and a Wood's lamp examination of the skin to asses for hypopigmented macules that may be indicative of Tuberous Sclerosis Complex or neurofibromatosis.
3. Developmental and/or psychometric evaluation to determine the child's overall level of functioning and whether a discrepancy between motor adaptive problem-solving and social communication skills exists.
4. Determination of the presence of a categorical DSM IV-TR diagnosis, preferably with standardized tools that operationalize the DSM criteria.
5. Assessment of the parents' knowledge of ASD, coping skills, and available resources.
6. A laboratory investigation to search for a known etiology or coexisting condition guided by information obtained in Steps 1-5 of the algorithm. (AAP 2007, pp 1203)

A search strategy might be conceptualized as consisting of 3 levels:

1. Studies that should be considered for all children (for example, an audiology evaluation)
2. Studies that should be considered in all children with both an ASD and coexisting global developmental delay or intellectual disability (e.g., testing for Fragile X syndrome)
3. Targeted studies (such as EEG, metabolic studies) should be considered when specific clinical findings are identified by history or physical examination. (AAP, 2007, pp 1205)

[16] Plauché Johnson, C., Myers, S.M., and the Council on Children with Disabilities. (2007). Identification and Evaluation of Children with Autism Spectrum Disorders. Pediatrics, Volume 120:5, pp 1203-1205.

- It is important that professionals assessing children with possible autism explain to parents the procedures and findings of the assessment in terms that are easily understood. This would include a full explanation of:
  - important terms and concepts used in reports
  - the results and implications of the assessment
  - comparison of the child's performance to developmental norms
- It is always good clinical practice for professionals to explain the results of their assessments to the child's parents. Such an explanation is particularly important for children with autism because their characteristically uneven developmental profile can be confusing. For example, a child may have age-level nonverbal skills and severely impaired communication skills.
- It is important for all professionals involved in the assessment of a child with possible autism to communicate with each other regarding their findings and recommendations.
- It may be useful to provide parents with recommendations about credible sources where they can obtain further information about autism.

NYSDOH Clinical Practice Guideline Recommendations on the General Approach for Establishing a Specific Diagnosis of Autism

Using autism assessment instruments to help make a diagnosis

Instruments specifically designed to assess autism in younger children (referred to here as "autism assessment instruments" and described in the section on assessment instruments) can be useful in assisting with the diagnosis of children suspected of having autism.

It is recommended that no single autism assessment instrument be used as the sole basis for diagnosing autism because:

- making a diagnosis of autism in children less than 3 years of age is complex.
- there is no single perfect method for diagnosing autism.

It is important to use multiple sources of information in assessing children suspected of having autism; it is especially important to include direct observation of the child.

Making a specific diagnosis of autism

Based on the practice acts of New York State, licensed psychologists, physicians, nurse practitioners, and clinical social workers are the only clinicians qualified to diagnose autism.

Since making an accurate diagnosis of autism is complex, particularly in children under 3 years of age, it is important that clinicians who make the diagnosis have experience and expertise in assessing young children with autism.

It is recommended that the diagnosis of autism be based on the criteria in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*, or the most current edition of this manual (see Appendix A).

The NYSDOH Clinical Practice Guideline provides extensive recommendations on Health Evaluations for Young Children with Autism. Although the guideline was issued in 1999, physician experts who reviewed and were consulted on this best practice protocol found the information and recommendations in this section to be useful and helpful for practicing pediatricians; thus, this section of the guideline is included as Appendix G of this best practice protocol. The NYSDOH Clinical Practice Guideline is in the process of being updated, with support from the FAR Fund, and will be reissued in 2013. Appendix G of the best practice protocol will be updated to reflect the most current research and information upon completion of this work.

Appendix A

Table 1: DSM-IV Diagnostic Criteria for 299.00 Autistic Disorder

A diagnosis of **autistic disorder** is made when the following criteria from A, B, and C are all met.

A A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (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. a lack of spontaneous seeking to share enjoyment, interests, or achievements with others (e.g., by a lack of showing, bringing, or pointing out objects 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 total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
    b. in individuals with adequate speech, marked 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, interest, and activities, as manifested by at least one of the following:*
    a. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
    b. apparently inflexible adherence to specific, nonfunctional routines or rituals
    c. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or 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.

Appendix A

Table 2: DSM-IV Diagnostic Criteria for PDD-NOS

A diagnosis of **pervasive developmental disorder, not otherwise specified (PDD-NOS)** is made 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. For example, this category includes "atypical autism" – presentations that do not meet the criteria for autistic disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

Table 3: DSM-IV Diagnostic Criteria for Asperger's Syndrome

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. a lack of spontaneous seeking to share enjoyment, interests, or achievements with others (e.g., by a lack of showing, bringing, or pointing out objects of interest)
4. lack of social or emotional reciprocity

B *Restricted, repetitive, and stereotyped patterns of behavior, interest, and activities, as manifested by at least one of the following:*

1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
2. apparently inflexible adherence to specific, nonfunctional routines or rituals
3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or 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 delay in language (e.g., single words used by 2 years old, communicative phrases used by 3 years old).

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 Developmental Disorder or Schizophrenia.

Appendix B

Reprinted from: New York State Department of Health, Early Intervention Program, 1999. *Report of the Recommendations: Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3 Years)*, pp 58-60.

Table III-5 lists behaviors used to identify children with autism that were shown to be clinical clues for autism in scientific studies meeting the criteria for adequate evidence about efficacy for this guideline. For each item listed, the table gives (1) the sensitivity and specificity for identifying autism versus other developmental problems and (2) the corresponding section of the **DSM-IV** criteria for autism. (See **Appendix A** for more information about sensitivity and specificity.)

Table III-5: Evidence-Based Clinical Clues for Possible Autism

TEST (author, year) **Clinical Clue**	**Ability to identify children with autism** *Sensitivity*	 *Specificity*	**Relevant section in DSM-IV**
ABC: (Oswald, 1991) age of subjects: 2.5 to 31 years			
Looks through people	69%	73%	(1A)
Not responsive to other people's facial expressions/feelings	65%	64%	(1A)
BSE: (Barthelemy, 1992) age of subjects: 2 to 8 years old			
Is eager for aloneness	60%	98%	(1D)
CHAT: (Baron-Cohen, 1996) age of subjects: all 18 months old			
Lack of proto-declarative pointing [a]	100%	100%	(1C)
Lack of gaze monitoring [b]	100%	100%	(1C)
Lack of pretend play	- not reported -		(2D)
Lacks all 3 of the above behaviors	100%	95%	(1C & 2D)
[a] pointing at an object to get another person to look at it; [b] following the gaze of another person who is looking at an object			
DSM-III-R: (Siegel, 1990) age of subjects: all < 4 years old			
Social interaction			
Not aware of others	80%	81%	(1D)
No comfort seeking	62%	78%	(1D)
Impaired imitation	78%	77%	(1C)

Appendix B

No social play	98%	44%	(2D)
No peer friends	100%	39%	(1B)
Communication			
No communication	37%	89%	(2A)
No nonverbal communication	85%	65%	(2A)
No imagination	81%	50%	(2D)
Abnormal speech	81%	50%	(2A)
Abnormal language	33%	63%	(2C)
Nonconversational	75%	50%	(2B)
Activities and interests			
Motor stereotypies	73%	71%	(3C)
Sensory preoccupation	40%	91%	(3A)
Distress over changes	44%	85%	(3B)
Insistence on routines	79%	66%	(3B)
Restricted interests	40%	83%	(3A)
Optimal solution			
Not aware of others and no peer friends	81%	84%	(1D & 1B)
ADI-R: (Lord, 1997) age of subjects: 2 to 43 years old			
Impairment in social interactions [c]			
Lack of social responsiveness	97%	39%	(1C)
Lack of social reciprocity	95%	48%	(1D)
Does not form friendships	96%	57%	(1B)
Lack of cooperative play [d]	94%	30%	(1C)
Lack of turn taking / imitation	96%	35%	(1C)
Unable to share pleasure	91%	48%	(1D)
Abnormal quality of social overtures	96%	57%	(1C)
Impairment in communication [c]			
Does not point to get desired objects	91%	47%	(1A)

Appendix B

Few expressive, inactive gestures	100%	26%	(1A)
Lack of nonverbal intentionality	95%	42%	(1A)
Limited initiation of activity/play	99%	67%	(2D)
Restricted, repetitive behaviors [c]			
Hand and finger mannerisms	89%	76%	(3C)
Limited curiosity in activities/play	99%	57%	(2D)
Limited sharing in others activities	91%	81%	(1C)

[c] Data are for nonverbal subjects and all ratings are for "current" behavior except as noted by [d] below.

[d] Scored as positive if the subject had "ever" had the behavior for at least a 3-month period when over 18 months mental age.

Appendix C - AAP Surveillance and Screening Algorithm: Autism Spectrum Disorders

Place cursor over flowchart symbol to view information about each step

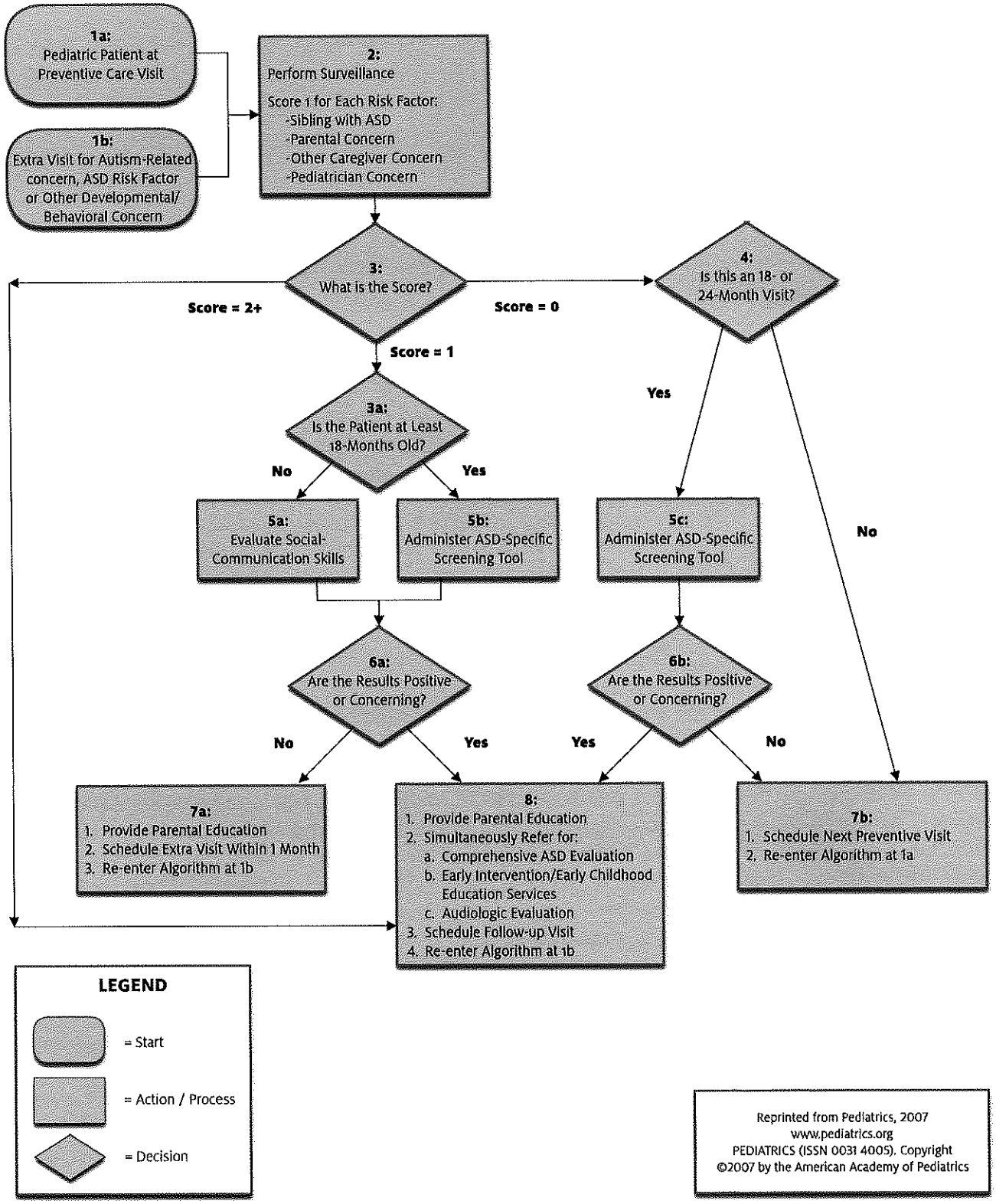

FIGURE 1
Surveillance and screening algorithm: ASDs.

Appendix D – MCHAT Reprint permissions, Instructions, and Screening

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 M-CHAT and supplemental materials can be downloaded from www.firstsigns.org or from Dr. Robins' website, at www.mchatscreen.com

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, instructions, or item order 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 for use by others (e.g., as part of digital medical record or other software packages) must contact Diana Robins to request permission (drobins@gsu.edu).
4. If you are part of a medical practice, and you want to incorporate the M-CHAT into your own practice's electronic medical record (EMR), you are welcome to do so. However, if you ever want to distribute your EMR page outside of your practice, please contact Diana Robins to request permission.

Instructions for Use

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 www.mchatscreen.com 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 3 or more items total or 2 or more critical items (particularly if these scores remain elevated after the M-CHAT 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.

Appendix D – MCHAT Reprint permissions, Instructions, and Screening

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**

Appendix E – Table 3, Selected Level 1 and Level 2 ASD Screening Measures

Screening Tool	Age	Format (No. of Items)	Time to Complete, min	Reported Sensitivity	Reported Specificity	Selected Key References	Availability
Level 1[a]							
CHAT	18–24+ mo	Parent interview or questionnaire and interactive (parent: 9; clinician: 5)	5	0.18–0.38[b]; 0.65[c]	0.98–1.0[b]; 1.0[c]	Baron-Cohen et al,[267] Baron-Cohen et al,[272] Baird et al,[19] Scambler et al[273]	Download: www.autismresearchcentre.com/tests/chat_test.asp
CHAT, Denver Modifications	18–24+ mo	Parent interview or questionnaire and interactive (parent: 9; clinician: 5)	5	0.85[c]	1.0[c]	Scambler et al[273]	CHAT scoring modifications; available in Scambler et al[273]
Checklist for Autism in Toddlers-23 (CHAT-23)	16–86 mo (all had mental ages of 18–24 mo)	Parent interview or questionnaire and interactive (parent: 23, clinician: 5)	10	0.84–0.93[c] (part A); 0.74[c] (part B)	0.77–0.85[c] (part A); 0.91[c] (part B)	Wong et al[274]	Combination of M-CHAT and CHAT items; protocol available in Wong et al[274]
CAST	4–11 y	Questionnaire completed by parent (37)	10	0.88–1.0[d]	0.97–0.98[d]	Scott et al,[275] Williams et al,[235] Williams et al[276]	Download: www.autismresearchcentre.com/tests/cast_test.asp
M-CHAT	16–48 mo	Questionnaire completed by parent (23)	5–10	0.85[d]	0.93[d]	Dumont-Matthieu and Fein,[277] Robins et al[268]	Download: www.dbpeds.org/media/mchat.pdf or www.firstsigns.org/downloads/m-chat.pdf; for scoring: www.firstsigns.org/downloads/m-chat_scoring.PDF
Pervasive Developmental Disorders Screening Test-II, Primary Care Screener (PDDST-II PCS)	18–48 mo	Questionnaire completed by parent (22)	10–15	0.92[c]	0.91[c]	Siegel[269]	Purchase: PsychCorp/Harcourt Assessment (www.harcourtassessment.com)
Level 2							
Asperger Syndrome Diagnostic Scale (ASDS)	5–18 y	Questionnaire completed by parent, teacher, or clinician (50)	10–15	0.85[c]		Myles et al,[278] Campbell[270]	Purchase: Pro-Ed (www.proedinc.com)
Autism Behavior Checklist (ABC)	≥18 mo	Behavioral checklist completed by interviewer (57)	10–20	0.38–0.58[c]	0.76–0.97[c]	Krug et al[279]	Purchase: Pro-Ed (www.proedinc.com) as part of the Autism Screening Instrument for Educational Planning (ASIEP-2)
Autism Quotient (AQ)–Adolescent Version	11–16 y	Questionnaire completed by parent (50)	15	0.89[c]	1.0[c]	Baron-Cohen et al[280]	Download: www.autismresearchcentre.com/tests/aq_adolescent_test.asp
Autism Spectrum Screening Questionnaire (ASSQ)	6–17 y	Questionnaire completed by parent (27)	10	0.62–0.82[c] (parent); 0.65–0.70[c] (teacher)		Ehlers et al[281]	Questions are included as an appendix in Ehlers et al[281]
Childhood Autism Rating Scale (CARS)	>2 y	Behavioral checklist completed by trained interviewer/ observer (15)	Variable	0.92–0.98[c]; 0.94[c]	0.85[c]	Eaves and Milner,[282] Perry et al,[283] Schopler et al[284], Sevin et al[285]	Purchase: Western Psychological Services (www.wpspublish.com)
Gilliam Asperger's Disorder Scale (GADS)	3–22 y	Questionnaire completed by parent, teacher, or clinician (32)	10			Gilliam,[286] Campbell[270]	Purchase: Pro-Ed (www.proedinc.com)
Gilliam Autism Rating Scale–2nd Edition (GARS-2)	3–22 y	Questionnaire completed by parent or teacher (42)	5–10			Gilliam[287]	Purchase: Pro-Ed (www.proedinc.com)
Krug Asperger's Disorder Index (KADI)	6–21 y	Questionnaire completed by parent or clinician (32)	15–20	0.78[c]	0.94[c]	Krug and Arick,[288] Campbell[270]	Purchase: Pro-Ed (www.proedinc.com)
Pervasive Developmental Disorders Screening Test-II, Developmental Clinic Screener (PDDST-II, DCS)	18–48 mo	Questionnaire completed by parent (14)	10–15	0.73[c]	0.49[c]	Siegel[269]	Purchase: PsychCorp/Harcourt Assessment (www.harcourtassessment.com)
Pervasive Developmental Disorders Screening Test-II, Autism Clinic Severity Screener (PDDST-II, ACSC)	18–48 mo	Questionnaire completed by parent (12)	10–15	0.58[c]	0.60[c]	Siegel[269]	Purchase: PsychCorp/Harcourt Assessment (www.harcourtassessment.com)
Screening Tool for Autism in Two-Year-Olds (STAT)	24–36 mo	Interactive, requires specific training (12)	20	0.92[d]	0.85[d]	Stone et al,[289] Stone et al[290]	Author: Wendy Stone, PhD (triad@vanderbilt.edu)
Social Communication Questionnaire (SCQ) (formerly the Autism Screening Questionnaire [ASQ])	≥4 y	Questionnaire completed by parent (40)	5–10	0.85–0.96[c]	0.67–0.80[c]	Berument et al,[291] Rutter et al[292]	Purchase: Western Psychological Services (www.wpspublish.com)

The measures were selected on the basis of availability of some published psychometric properties (in English) with scoring instructions and pass/fail cutoffs or the equivalent.

[a] Level 1 tools are most likely to be used in primary care settings.

[b] Population-based sample.

[c] Clinical sample.

[d] Clinical and population-based samples.

Adapted from Coonrod EE, Stone WL. Screening for autism in young children. In: Volkmar FR, Paul R, Klin A, Cohen D, eds. *Handbook of Autism and Pervasive Developmental Disorders*. 3rd ed. Vol 2. Hoboken, NJ: John Wiley & Sons; 2005:707–729; Campbell JM. Diagnostic assessment of Asperger's disorder: a review of five third-party rating scales. *J Autism Dev Disord*. 2005;35:25–35; and Rutter M, Bailey A, Lord C, et al. *The Social Communication Questionnaire (SCQ) Manual*. Los Angeles, CA: Western Psychological Services; 2003.

Appendix F – List of Municipal EIPs

Albany County Department for Children, Youth and Families

112 State Street, Room 300
Albany, New York 12207
Main: 518-447-4820
Fax: 518-447-4855

Allegany County Health Department

7 Court Street Rm 19
Belmont, New York 14813
Main: 585-268-9767
Fax: 585-268-9598

Broome County Health Department

225 Front Street
Binghamton, New York 13905
Main: 607-778-2851
Fax: 607-778-2864

Cattaraugus County Health Department

1 Leo Moss Drive, Suite 4010
Olean, New York 14760
Main: 716-373-8050
Fax: 716-701-3737

Cayuga County Health Department

8 Dill Street
Auburn, New York 13021-3424
Main: 315-253-1560
Fax: 315-253-1156

Chautauqua County Health Department

7 North Erie Street
Mayville, New York 14757
Main: 716-753-4491
Fax: 716-753-4794

Chemung County Social Services Department

Human Resource Center
PO Box 588
425-447 Pennsylvania Avenue
Elmira, New York 14902-0588
Main: 607-737-5568
Fax: 607-737-5480

Chenango County Health Department

Chenango County Office Building
5 Court Street
Norwich, New York 13815
Main: 607-337-1729
Fax: 607-337-1720

Clinton County Health Department

133 Margaret Street
Plattsburgh, New York 12901
Main: 518-565-4798
Fax: 518-565-4509

Columbia County Health Department

325 Columbia Street
Hudson, New York 12534
Main: 518-828-4278, Ext. 1303/1305
Fax: 518-671-6738

Cortland County Health Department

60 Central Avenue
Cortland, New York 13045-2746
Main: 607-756-3439
Fax: 607-753-5136

Delaware County Public Health Nursing Service

99 Main Street
Delhi, New York 13753
Main: 607-746-3166
Fax: 607-746-3243

Dutchess County Health Department

510 Haight Avenue, Suite 105
Poughkeepsie, New York 12603
Main: 845-486-2759
Fax: 845-486-3554

Erie County Health Department

95 Franklin Street, Room 828
Buffalo, New York 14202
Main: 716-858-6161
Fax: 716-858-6892

Appendix F – List of Municipal EIPs

Essex County Public Health Nursing Service

PO Box 217
132 Water Street
Elizabethtown, New York 12932-0217
Main: 518-873-3522
Fax: 518-873-3539

Franklin County Public Health Nursing Service

355 West Main Street
Malone, New York 12953
Main: 518-481-1709
Fax: 518-483-9378

Fulton County Public Health Department

PO Box 415
2714 County Highway 29
Johnstown, New York 12095-0415
Main: 518-736-5720
Fax: 518-762-1382

Genesee County Health Department

3837 West Main Street
Batavia, New York 14020-9406
Main: 585-344-2580, Ext. 5572
Fax: 585-344-4713

Greene County Public Health Nursing Service

411 Main Street, 3rd Floor
Catskill, New York 12414
Main: 518-719-3600
Fax: 518-719-3781 or 518-719-3782

Hamilton County Public Health Nursing Service

PO Box 250
White Birch Lane
Indian Lake, New York 12842
Main: 518-648-6497
Fax: 518-648-6143

Herkimer County Public Health Nursing Service

301 North Washington Street
Herkimer, New York 13350
Main: 315-867-1176
Fax: 315-867-1431

Jefferson County Community Services

175 Arsenal Street
Watertown, New York 13601
Main: 315-785-3283
Fax: 315-785-5182

Lewis County Public Health Agency Children Services

7785 North State Street
Lowville, New York 13367
Main: 315-376-5849
Fax: 315-376-5462

Livingston County Health Department

Murray Hill Drive
Mount Morris, New York 14510
Main: 585-243-7290
Fax: 585-243-7287

Madison County Public Health Department

PO Box 605
County Office Building #5
Wampsville, New York 13163
Main: 315-366-2361
Fax: 315-366-2847

Monroe County Human & Health Services Department

691 Saint Paul Street, 4th Floor
Rochester, New York 14605-1798
Main: 585-753-5274
Fax: 585-753-5272

Montgomery County Public Health

PO Box 1500
Park Street County Annex Building
Fonda, New York 12068-1500
Main: 518-853-3531
Fax: 518-853-8218

Nassau County Health Department

60 Charles Lindberg Blvd., Suite 100
Uniondale, New York 11553-3683
Main: 516-227-8661
Fax: 516-227-8662

Appendix F – List of Municipal EIPs

New York City Department of Health and Mental Hygiene

Gotham Center, CN # 12
42-09 28th Street, 18th Floor
Long Island City, NY 11101-4132
Phone Number in NYC Dial 311
If outside NYC: 212-639-9675
Fax: 347-396-6928

Bronx (Bronx County)

1309 Fulton Avenue, 5th Floor
Bronx, NY 10456
Phone: 718-410-4110
Fax: 718-410-4480

Brooklyn (Kings County)

16 Court Street, 2nd & 6th Floor
Brooklyn, NY 11241
Phone: 718-722-3310
Fax: 718-722-7767, 718-722-7766

Manhattan (New York County)

42 Broadway, Suite 1027
New York, NY 10004
Phone: 212-487-3920
Fax: 212-487-3930

Queens (Queens County)

59-17 Junction Blvd. 2nd Floor
Corona, NY 11368
Phone: 718-271-1003
Fax: 718-271-6114, 718-271-6271

Staten Island (Richmond County)

51 Stuyvesant Place
Staten Island, NY 10301
Phone: 718-420-5350
Fax: 718-420-5360, 718-420-5364

Niagara County Health Department

Trott Access Center
1001 11th Street
Niagara Falls, New York 14301
Main: 716-278-1991
Fax: 716-278-8288

Oneida County Health Department

800 Park Avenue, 3rd Floor
Utica, New York 13501
Main: 315-798-6400
Fax: 315-731-3491

Onondaga County Health Department

501 East Fayette Street, Suite B
Syracuse, New York 13202
Main: 315-435-3230
Fax: 315-435-2678

Ontario County Community Health Services

3019 County Complex Drive
Canandaigua, New York 14424
Main: 585-396-4439
Fax: 585-396-4551

Orange County Health Department

124 Main Street
Goshen, New York 10924
Main: 845-291-2333
Fax: 845-291-2418

Orleans County Health Department

14012 Route 31 West
Albion, New York 14411
Main: 585-589-2777
Fax: 585-589-3169

Oswego County Health Department

70 Bunner Street
Oswego, New York 13126
Main: 315-349-3510
Fax: 315-349-3537

Otsego County Health Department

Meadows Office Building
140 Country Highway 33W, Suite 3
Cooperstown, New York 13326-1129
Main: 607-547-6474
Fax: 607-547-6402

Putnam County Health Department

110 Old Route 6, Building 3
Carmel, New York 10512
Main: 845-808-1640, Ext. 46031
Fax: 845-225-1580

Appendix F – List of Municipal EIPs

Rensselaer County Health Department

Ned Pattison Government Center
1600 Seventh Avenue
Troy, New York 12180
Main: 518-270-2626
Fax: 518-270-2638

Rockland County Health Department

50 Sanatorium Road, Building J
Pomona, New York 10970
Main: 845-364-2620
Fax: 845-364-2093

Saratoga County Public Health Nursing Service

31 Woodlawn Avenue
Saratoga Springs, New York 12866
Main: 518-584-7460, Ext. 390
Fax: 518-583-2498

Schenectady County Public Health Services

107 Nott Terrace, Suite 306
Schenectady, New York 12308
Main: 518-386-2815
Fax: 518-386-2801

Schoharie County Health Department

PO Box 667
276 Main Street
Schoharie, New York 12157-0667
Main: 518-295-8705
Fax: 518-295-8786

Schuyler County Home Health Agency

Mill Creek Center
106 South Perry Street
Watkins Glen, New York 14891
Main: 607-535-8140
Fax: 607-535-8157

Seneca County Health Department

31 Thurber Drive, Suite 1
Waterloo, New York 13165-1660
Main: 315-539-1920
Fax: 315-539-9493

St. Lawrence County Public Health Department

80 State Highway 310, Suite 2
Canton, New York 13617
Main: 315-386-2325
Fax: 315-386-2744

Steuben County Public Health and Nursing Services

3 East Pulteney Square
Bath, New York 14810-1560
Main: 607-664-2146
Fax: 607-664-2197

Suffolk County Health Services

50 Laser Court
Hauppauge, New York 11788
Main: 631-853-3100
Fax: 631-853-2300

Sullivan County Public Health Nursing Service

PO Box 590
50 Community Lane
Liberty, New York 12754
Main: 845-292-0100, Ext.1
Fax: 845-292-1417

Tioga County Health Department

1062 State Route 38
PO Box 120
Owego, New York 13827-0120
Main: 607-687-8600
Fax: 607-687-8486

Tompkins County Health Department

55 Brown Road
Ithaca, New York 14850
Main: 607-274-6644
Fax: 607-274-6648

Ulster County Social Services Department

1061 Development Court
Kingston, New York 12401-1959
Main: 845-334-5251
Fax: 845-334-5227

Appendix F – List of Municipal EIPs

Warren County Health Services

Warren County Municipal Center
1340 State Route 9
Lake George, New York 12845
Main: 518-761-6580
Fax: 518-761-6422

Washington County Public Health Service

415 Lower Main Street
Hudson Falls, New York 12839-2650
Main: 518-746-2400
Fax: 518-746-2410

Wayne County Public Health

1519 Nye Road, Suite 200
Lyons, New York 14489
Main: 315-946-5749
Fax: 315-946-7057

Westchester County Health Department

145 Huguenot Street, 8th Floor
New Rochelle, New York 10801
Main: 914-813-5094
Fax: 914-813-5093

Wyoming County Health Department

8 Perry Avenue
Warsaw, New York 14569
Main: 585-786-8850
Fax: 585-786-8852

Yates County Health Department

417 Liberty Street, Suite 2120
Penn Yan, New York 14527
Main: 315-536-5160
Fax: 315-536-5146

Appendix F – State Referral Form

NEW YORK STATE DEPARTMENT OF HEALTH
Early Intervention Program

Referral Form for Children At-Risk or Suspected of Developmental Delay or Disability or With a Confirmed Disability

Instructions: This form may be used to refer a child under three years of age who is at risk for or suspected of having a developmental delay or disability or has a confirmed disability. The referral must be made via telephone, facsimile, or mail to the Early Intervention Official in the child's county of residence within two working days of the child's identification.

Report Date ☐☐ mo ☐☐ day ☐☐ yr

Referral Source

Person making referral	last	first	MI
Agency/Facility			
Address street		city	
state	zip	Telephone ( ) Ext.	

Child's Information

Child's Name	last	first	MI
Also known as	last	first	MI
Child's Address street		city	
Birthdate ☐☐ mo ☐☐ day ☐☐ yr	Sex F ☐ M ☐	Dominant language used	
County of residence			

Family Information

Name of Parent(s) or Legal Guardian	last	first	MI	last	first	MI
Address street			city			
state	zip	Telephone ( ) Ext.				
Relationship to Child		Dominant language used				

Alternate Contact (Through Whom the Parent May Be Contacted)

Alternate name	last	first	MI
Relationship to child	Telephone ( ) Ext.		

Reason for Referral (Please check [✔] only one)

☐ This child is being referred because he or she has a **confirmed disability** or is **suspected** of having a disability, which includes a developmental delay and/or a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay.

☐ This child is NOT suspected of having a disability at the present time but is being referred because he or she is **at risk** of developing a disability in the future.

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Appendix F – State Referral Form

Child's name (last / first / MI)	Birthdate (mo / day / yr)

THIS INFORMATION IS TO BE TRANSMITTED WITH INFORMED PARENTAL CONSENT*

Primary Health Care Provider	Telephone ( ) Ext.

STATUS AT TIME OF REFERRAL

Currently hospitalized: ___ NICU ___ PICU ___ Other ___ Facility Name: ___	___ Not hospitalized	Discharge date (mo / day / yr)

Diagnosed Conditions and/or Other Comments

Please specify

Suspected Delay (Please check [✔] all that apply)

- ☐ Cognitive
- ☐ Physical (including vision and hearing)
- ☐ Communication
- ☐ Social/emotional
- ☐ Adaptive

"At-Risk" Criteria (Check the box of each condition identified. Refer to Glossary of Risk Indicators. Copies may be obtained by contacting the Early Intervention Program at the New York State Department of Health at (518) 473-7016.)

Neonatal Risk Criteria

- ☐ Birth weight <1501 grams
- ☐ Gestational age <33 weeks
- ☐ CNS insult or abnormality
- ☐ Asphyxia (Apgar score of ≤ 3 at 5 minutes)
- ☐ Abnormalities in muscle tone
- ☐ Hyperbilirubinemia (>20 mg/dl)
- ☐ Hypoglycemia (<20 mg/dl)
- ☐ Growth deficiency/nutritional problems
- ☐ Inborn Metabolic Disorder (IMD)
- ☐ Perinatally - congenitally transmitted infection
- ☐ >10 days in Neonatal Intensive Care Unit (NICU)
- ☐ Maternal prenatal alcohol abuse
- ☐ Maternal prenatal abuse of illicit substances
- ☐ Prenatal exposure to certain therapeutic drugs with known potential developmental implications
- ☐ Maternal PKU
- ☐ Suspected hearing impairment
- ☐ Suspected vision impairment

Post-neonatal and Early Childhood Risk Criteria

- ☐ Parental/caregiver concern about developmental status
- ☐ Suspect score on developmental/sensory screening
- ☐ Serious illness/traumatic injury with implications for CNS
- ☐ Elevated blood lead levels (above 19 mcg/dl)
- ☐ Growth deficiency/nutritional problems
- ☐ Chronicity of serous otitis media (Continuous for minimum of 3 months)
- ☐ HIV infection

Other Risk Criteria that May Be Considered

- ☐ No prenatal care
- ☐ Parental developmental disability/mental illness
- ☐ Parental substance abuse
- ☐ No well child care by age 6 months
- ☐ Other, please specify ___

Parental/Legal Guardian Consent

I consent to the release of the above information to:

Name: ___

Title : ___

Early Intervention Official
Early Intervention Program

___
Signature

Date ___/___/___

County/municipality: ___

* Above signature may be used for parental consent purposes. Parental consent may also be obtained with an existing protocol or form routinely used by the referral source that legally authorizes transmittal of this information to the Early Intervention Program.

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Appendix G

General Approach for the Health Evaluation of Children with Possible Autism**

Reprinted from: New York State Department of Health, Early Intervention Program, 1999. Report of the Recommendations: Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3 Years), pp 91-107.

The diagnosis of autism is made based on historical information about and direct observation of a child's behavior (in terms of communication, social interactions, and maladaptive behaviors). Most experts on autism agree that there are currently no specific laboratory, imaging, electrophysiological or other medical tests that can be used to establish the diagnosis of autism.

However, there are several well-accepted reasons why it is important to perform general and specific health evaluations of young children with possible autism. There are also controversial methods that have been proposed for assessing children with autism. Both well-accepted health assessment methods and those that are more controversial are discussed in this section.

**The NYSDOH Clinical Practice Guideline provides extensive recommendations on Health Evaluations for Young Children with Autism. Although the guideline was issued in 1999, physician experts who reviewed and were consulted on this best practice protocol found the information and recommendations in this section to be useful and helpful for practicing pediatricians; thus, this section of the guideline is included as Appendix G of this best practice protocol. The NYSDOH Clinical Practice Guideline is in the process of being updated, with support from the FAR Fund, and will be reissued in 2013. Appendix G of the best practice protocol will be updated to reflect the most current research and information upon completion of this work.

Primary reasons for health evaluations of children with possible autism

There are three primary reasons generally accepted by the professional community for doing health evaluations of children with autism. These are:

- to provide a general assessment of the child's health status (as is recommended for all children with possible developmental delays or disorders)
- to identify other conditions (such as hearing loss) that are sometimes confused with autism, in a child who does not have autism
- to identify and assess medical conditions or genetic syndromes that are sometimes associated with autism

Aspects of health evaluations reviewed in this section

It would be an extremely large task to evaluate the efficacy of all possible methods for assessing health status in children with possible autism. Therefore, the scope of this section is limited to the following:

- the general health evaluation process for children with possible autism
- a few specific assessment methods used to identify some of the more common associated health conditions seen in children with autism

- some controversial assessment methods for children with autism that are of current concern to parents and professionals

Assessing associated health conditions sometimes seen in children with autism

An important purpose of a comprehensive health evaluation for children with suspected autism is to identify possible associated medical conditions that are seen more commonly in children with autism than in the general population. These associated medical conditions include a variety of neurological problems (such as seizure disorders), genetic syndromes (such as Fragile X syndrome, a specific genetic disorder that is sometimes associated with the clinical picture of autism) and metabolic disorders. Table III-8 provides a list of medical conditions and syndromes that are more common in children with autism than in the general population.

Some of the health conditions associated with autism may benefit from early identification and appropriate treatment. For example, seizure disorders, hypothyroidism and some metabolic disorders are important to diagnose and treat as early as possible. In other cases, there may be no specific treatment for a condition, but identifying the condition may still be beneficial. For example, for some genetic conditions associated with autism (such as Fragile X syndrome), the primary benefit of early identification may be to provide appropriate genetic counseling to the parents.

This section of the guideline includes recommendations about specific methods for assessing hearing problems, seizures and Fragile X syndrome, which are three of the more common associated health conditions seen in children with autism. While there is an extensive scientific literature on each of these three topics, the relevant literature was not systematically reviewed because:

1. the methods for assessing these associated conditions are well established
2. these topics are not particularly controversial
3. detailed information on these topics is considered to be readily available to interested professionals

Controversial methods of health assessment for children with possible autism

Another more controversial use of health assessment methods that has been proposed is the use of specific immune, allergic, or metabolic tests to identify subgroups of children with autism who may respond to specific medication or dietary interventions.

The justifications for such testing are based on various controversial theories about the causation of autism. The proponents of these medical tests maintain that in some children autism may be caused by certain immune, allergic, or metabolic processes related to diet, yeast infections, prior viral infections, or other causes. These theories are not generally accepted in the scientific community. Although it is generally accepted that autism is a biologically based condition affecting the central nervous system, extensive biological research has not yet identified any specific anatomical or biochemical findings considered to cause autism.

Systematic literature evaluations were done for the specific health assessment methods that are considered to be areas of current controversy. While some of these assessment methods, such as allergy testing, are well established as general diagnostic tools for specific health conditions, the use of these assessment methods in children with autism

can be controversial. For some of these assessment methods an extensive scientific literature exists. For other topics, very little published scientific research is available, but the methods are discussed extensively by parents and others in the community.

Evaluating the use of MRI scans

One of the specific medical assessment methods evaluated in this chapter is the use of magnetic resonance imaging (MRI) scans to evaluate children with autism. There are many studies in the literature on the use of MRI scans in persons with autism to identify associated neurological conditions, such as tumors. These articles were not included in the literature review because evaluation of the efficacy of MRI scans for identifying tumors and neuropathology is well established and is beyond the scope of the guideline. However, the guideline panel did review studies that evaluated the structural anatomy of the brain seen on MRI scans in children with autism compared to children without autism. These studies were reviewed to assess if MRI scans offered any information that would be useful for either estimating prognosis or guiding treatment decisions in persons with autism.

Evaluating the use of other medical assessments

Topics included in this section include:

- immune status
- food allergies
- lab tests to look for yeast overgrowth

The remaining parts of this section evaluate certain medical assessment methods purporting to identify subgroups of children with autism who may respond to specific interventions. Identifying such subgroups is the usual rationale given by proponents of assessing immune status, food allergies, and urinary organic acid metabolites to look for yeast overgrowth in individuals with autism. Proponents of these testing methods also maintain that individuals with autism who have positive results on these tests may respond to special immunological, diet, or anti-yeast therapies.

These assessment methods and associated treatments, as well as the theories they are based on, are all controversial. However, these controversial assessment methods are included in order to provide evidence-based recommendations to parents and professionals who may be considering the use of these methods.

Table III-8: Medical Conditions and Syndromes Seen More Frequently in Children with Autism than in the General Population

Cytomegalovirus infection
Duchenne muscular dystrophy
Encephalitis
Fragile X syndrome
Haemophilus influenza meningitis
Herpes simplex encephalitis
Hypomelanosis of Ito
Hypothyroidism
Lactic acidosis
Maternal rubella
Multiple congenital abnormalities / Mental retardation syndrome
Moebius syndrome
Mucopolysaccharidosis
Neurofibromatosis
Other autosomal chromosome abnormalities
Other sex chromosome abnormalities
Partial tetrasomy 15 syndrome
Phenylketonuria
Purine disorders
Rett's disorder
Seizures
Sotos syndrome
Tuberous sclerosis
West syndrome
Williams syndrome

Adapted from Gilberg and Coleman, 1996

Recommendations

Importance of the general health evaluation for children with possible autism

1. It is important that all children with suspected developmental problems have a comprehensive health evaluation.

2. It is important to carry out a comprehensive health evaluation for children with possible autism in order to:

   - screen for disease and assess suspected health problems
   - look for associated medical conditions or genetic syndromes that are not part of autism but are seen more frequently in children with autism
   - look for evidence of other developmental problems, since these are more frequently seen in children with autism than in typically developing children
   - aid in assessing the child's level of development
   - aid in planning of interventions and assessing health outcomes from interventions

Components of the health examination

3. It is important to recognize that children with autism are susceptible to all the same health and medical problems as children without autism.

4. It is important to recognize that health care for children with autism may present special challenges for health care providers and parents.

5. It is important that a general health evaluation for children with possible autism include at least the following components:

   - assessment of hearing and vision
   - a neurological evaluation
   - a skin exam (for signs of tuberous sclerosis or neurofibromatosis)
   - a search for medical conditions, genetic syndromes, or other developmental problems that are sometimes associated with autism
   - elements of routine developmental surveillance and general health screening appropriate for the child's age
   - assessment of other current health problems
   - addressing any other health concerns expressed by the parents

Role of the health evaluation in diagnosing autism

6. In assessing a child where autism is suspected but has not yet been diagnosed, it is important to recognize that:
   - The diagnosis of autism is made based on historical information about and direct observation of a child's behavior (in terms of communication, social interactions and maladaptive behaviors).
   - Most experts on autism agree that there are no specific laboratory, imaging, electrophysiological or other medical tests that can be used to establish the diagnosis of autism.
   - There are currently no laboratory tests or clinical assessment methods that are useful for identifying subgroups of children with autism that respond to specific medications, immune, or dietary interventions.
7. As part of the process of diagnosing autism, it is important to:
   - help identify and adequately assess any associated medical conditions or genetic syndromes that are not part of autism but are seen more frequently in children with autism than in the general population
   - help identify other medical conditions and developmental problems that are sometimes mistaken for autism in children who do not have autism

Explaining the health assessment to parents and obtaining informed consent

8. It is important that professionals carrying out the health evaluation of children with possible autism discuss the findings of the evaluation with the child's parents.
9. In cases where a health assessment procedure is associated with some potential physical harm, it is important that professionals obtain appropriate informed consent from the child's parents prior to performing the test.

Tests to Identify Health Conditions Associated with Autism

Recommendations

Looking for associated health conditions

1. It is recommended that professionals assessing health status of children with autism actively look for associated health conditions (listed in Table III-8) seen more commonly in children with autism than in typically developing children.

Evaluation of hearing status

2. It is extremely important to establish the hearing status in a child with suspected or diagnosed autism to rule out hearing impairment as a contributing factor for the child's communication problems.
3. If there is any indication that a child with suspected or diagnosed autism has a hearing problem, it is important to refer the child for a hearing evaluation by an audiologist (including brain stem evoked response testing if appropriate).

Testing for Fragile X syndrome

4. In most children with suspected or diagnosed autism, it is useful to do an appropriate laboratory test for Fragile X syndrome in order to determine:
   - possible appropriate interventions
   - if genetic counseling is appropriate for the parents
5. It is useful to recognize that Fragile X syndrome is less likely to be found in children with autism who have average or above average intelligence.
6. In doing laboratory testing for Fragile X syndrome, it is recommended that a test be used which has established clinical validity and reliability (such as, a specific DNA probe test).

Testing for seizures

7. In children with suspected or diagnosed autism, electro-encephalograms (EEGs), including possibly a sleep EEG, may be useful when there is an increased likelihood or clinical suspicion of possible seizures, including:
   - a clinical history suggesting seizures
   - an associated neurological abnormality
   - a clinical picture of Landau-Kleffner syndrome (a specific condition in which the child has a form of epilepsy and also does not talk)
   - in the clinical judgment of the physician it is important to rule out seizures
8. An EEG is not useful for making the diagnosis of autism.

Magnetic Resonance Imaging (MRI)

Magnetic resonance imaging (MRI) scans of the head use strong electromagnetic fields to produce cross-sectional images of the head and brain. MRI scans do not involve ionizing radiation (such as x-rays or radioactive isotopes). Computer-generated cross-sectional images of the head and brain are produced in three geometric planes (coronal, frontal and sagittal). MRI scans provide information about the structural anatomy of the brain that can be used to detect abnormal anatomical structures, tumors, infections, traumatic injuries, and other pathological changes in the brain.

When a MRI scan is being done, the individual must remain still for about 45 minutes while lying on a table with the head inside a circular electromagnetic coil. The procedure almost always requires sedation for children under 3 years old. MRI scans are associated with minimal risks except for those related to sedation for the procedure.

Recommendations

1. Magnetic resonance imaging (MRI) scans may be useful in certain clinical situations in assessing children with autism when there is heightened concern about focal neurological problems, such as seizures.
2. MRI scans may be useful in assessing some children at risk for neurological problems, such as children with a history of perinatal problems (health or medical problems that occurred during pregnancy or around the time of birth).
3. The use of MRI scans is not recommended in the routine assessment of children with possible autism.

Assessment of Immune Status

The main function of the immune system is to differentiate between the self and foreign elements. A breakdown of self-recognition mechanisms, or autoimmunity, is characterized by cellular and/or humoral immunological reactions against the self. All of the studies of immune status in individuals with autism have been done to investigate if the immune status in these individuals is different than in individuals without autism. None of the studies found in the literature was designed specifically to see if evaluating immune status was useful for identifying young children with possible autism. However, since this was the question of interest to the panel, relevant information from these studies was used to evaluate the usefulness of evaluating immune status in assessing children with autism.

Studies in autistic subjects have focused on measuring cellular elements of the immune system (particularly T-cells and NK-cells) or measuring humoral immunity (particularly immunoglobulin levels or specific autoantibodies).

Recommendations

1. Evaluating immune status is not recommended in the routine assessment of children with autism.

Food-Allergy and Diet Assessment

An allergy is an immunological sensitization to a specific foreign material that originates outside the person. Allergies are not inherited but must be acquired. Upon exposure to certain foreign materials, a person can become sensitized and then later develop allergic reactions when re-exposed to that substance. The majority of individuals are not allergic to any specific substance, and it is unclear why some persons develop an allergy after exposure to a material while others with the same type of exposure do not develop an allergy.

The most common types of allergic conditions are allergic rhinitis (hay fever) and allergic asthma. Allergic reactions can also occur to a variety of foods. However, in young children food allergies are much less common than allergic rhinitis or allergic asthma. The most common types of reactions from food allergies are nasal congestion and hives. Some individuals with severe food allergies do sometimes develop systemic allergic reactions and anaphylaxis. There are also other types of digestive or malabsorption problems that are not allergic conditions (such as lactose intolerance, an inability to digest milk products based on an enzyme deficiency rather than an allergy to milk).

The usual method to test for food allergies is to do skin prick or scratch testing. This involves placing a drop of sterile solution containing a very small amount of the allergen on the subject's skin, and then scratching or pricking the skin with a needle to introduce some of the solution under the skin. An alternative method of testing for allergies is to inject a small amount of the solution just below the surface of the skin (intradermal injection). This technique is used both for airborne allergens and food allergens.

Another method of testing for allergies is to check the person's blood for antibodies to the particular foreign substance. This method is considered by many experts to have lower accuracy, resulting in both more false positive and more false negative tests. Moreover, the validity (sensitivity and specificity) and reliability of these antibody tests appears to vary greatly depending on the individual allergen and test method being evaluated.

Elimination diets are also sometimes proposed as a method for detecting food allergies. These involve having a subject eliminate certain foods from the diet that are suspected of possibly causing allergic problems. After these foods have been eliminated for several weeks, each suspect food is then added back into the diet one at a time (this is referred to as a food challenge). Proponents of this approach suggest that if a subject's symptoms of concern improve during the food elimination stage, and then worsen again after a food is reintroduced, this suggests the individual is allergic to that particular food. Many allergy experts consider the use of elimination diets and food challenges to be controversial, and question the validity of these procedures for diagnosing food allergies.

Recommendations

1. Testing for food allergies is not recommended in the routine assessment of children with possible autism.
2. It is recommended that children with possible autism be treated no differently than other children in the assessment of food allergies. Testing for food allergies may be useful in some children if there is a heightened concern about allergies.

Assessment of Organic Acid Metabolites to Detect Yeast Overgrowth

This assessment method involves laboratory analysis of a urine specimen for specific organic acid metabolites. The proposed rationale for such testing is based on the controversial theory that in some persons an overgrowth of yeast in the intestinal tract can cause or aggravate autism. Proponents of this theory suggest that an overgrowth of yeast in the intestinal tract can occur after the use of antibiotics or in certain susceptible individuals. They further maintain that this overgrowth of yeast leads to the systemic absorption of yeast metabolites, which then causes or aggravates manifestations of autism. These yeast metabolites are then said to be excreted in the urine as specific organic acids.

Proponents of this theory maintain that for a person with autism, high levels of specific organic acids in the urine suggest that an overgrowth of yeast in the intestinal tract may have caused or aggravated the autism. Proponents also suggest that in these individuals anti-yeast therapy may bring about an improvement in autism.

Recommendations

❶ Testing for specific organic acids in the urine as a means to identify an overgrowth of yeast in the intestinal tract is not recommended in the assessment of children with possible autism.