

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



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Table of Contents

INTRODUCTION	3
WHAT ARE AUTISM SPECTRUM DISORDERS?	4
WHAT ARE THE SYMPTOMS OF ASDs?	5
GENERAL APPROACH TO EARLY IDENTIFICATION OF YOUNG CHILDREN WITH AUTISM	6
Importance of Early Identification of Autism	6
Identifying Initial Concerns About Possible Autism	6
GENERAL PRINCIPLES OF SCREENING AND SURVEILLANCE FOR YOUNG CHILDREN	7
Developmental and Autism Screening.....	7
Developmental Surveillance	8
Importance and Timing of Developmental Surveillance	8
Components of Developmental Surveillance.....	8
Assessing Developmental Milestones That are Relevant to Autism.....	9
Developmental Milestones for Communication and Social Skills.....	9
Identifying Clinical Clues of Possible Autism.....	10
How Can Physicians Conduct Screening and Surveillance for ASDs in Their Regular Practice.....	14
SYNOPSIS OF THE AMERICAN ACADEMY OF PEDIATRICS (AAP) - SURVEILLANCE AND SCREENING ALGORITHM FOR ASDs	15
DIAGNOSTIC CHALLENGES AND RECOMMENDATIONS FOR COMPREHENSIVE ASSESSMENT	22
RECOMMENDATIONS FROM THE NYSDOH CLINICAL PRACTICE GUIDELINE ON COMMUNICATING FINDINGS WITH PARENTS AND OTHER PROFESSIONALS	23
NYSDOH CLINICAL PRACTICE GUIDELINE RECOMMENDATIONS ON THE GENERAL APPROACH FOR ESTABLISHING A SPECIFIC DIAGNOSIS OF AUTISM	24
NYSDOH EARLY INTERVENTION PROGRAM	25

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

In 2018, Section 2500-J of PHL was amended to require the addition of information about developmental screening. The ***Best Practice Protocol*** is updated to include new information about developmental screening and to reflect updates to the Diagnostic and Statistical Manual (DSM) and the NYSDOH Clinical Practice Guideline on Assessment and Intervention Services for Young Children with Autism Spectrum Disorders.

¹Issued in 1999, the NYSDOH guideline was the first evidence-based guideline addressing assessment and intervention for young children with autism. The guideline was updated by the Department with support from the FAR Fund and was re-issued in 2017 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.

Introduction

The following symbols are used to denote recommendations from:



AAP

or



NYSDOH

What are Autism Spectrum Disorders?

ASDs represent three of the pervasive developmental disorders defined in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V).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.

It is estimated that between 1 in 40 and 1 in 59 children meet the diagnostic criteria for Autism Spectrum Disorders.³

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 Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, 2013. American Psychiatric Association.

³ Cited from www.cdc.gov/ncbddd/autism/index.html, accessed on October 17, 2018.

What are the Symptoms of ASDs?

There are five criteria for the diagnosis of ASDs as defined in DSM-V:

- A. Persistent deficits in social communication and interactions in different environments and with different people, including reduced social-emotional reciprocity, not having back-and-forth interactions, not sharing interests, objects or emotions; reduced nonverbal communication, abnormal eye contact or lack of facial expressions; and difficulty with relationship development and maintenance, imaginary play, and making friends.
- B. Restricted, repetitive behavior, interests or activities, including at least two of the following:
 - 1) stereotyped or repetitive motor movements, speech or object use (e.g., echolalia, hand flapping, toe walking, spinning);
 - 2) inflexibility around routines (e.g., getting extremely upset with change, difficulty transitioning to new activities, insistence on eating same food or traveling the same route).
- C. Symptoms in criteria A and B are present in early developmental period.
- D. Symptoms in criteria A and B lead to clinically significant impairment
- E. An intellectual disability or global developmental disorder does not better explain the symptoms and deficits. To distinguish when an intellectual disability and ASD are present, social communication should be evaluated and determined to be below the expected level for general development.

DSM-V specifies that the severity of criteria A and B each be specified using the following categories:

- Level 1: requiring support
- Level 2: requiring substantial support
- Level 3: requiring very substantial support

Additional specificity can be included to clarify whether the diagnosis of ASD includes:

- Intellectual impairment
- Language impairment
- Known medical or genetic condition or environmental factor
- Neurodevelopmental, mental, or behavioral disorder
- Catatonia

The ASD criteria have been updated significantly in DSM-V. Diagnoses included in DSM-IV of autistic disorder, Asperger's disorder, and pervasive developmental disorder-not otherwise specified (PDD-NOS) are not included in DSM-V. There is a directive that individuals with established diagnoses using DSM-IV criteria should be given a diagnosis of ASD. Individuals with a deficit in social communication but without other symptoms of ASD should be evaluated for social (pragmatic) communication disorder.

General Approach to Early Identification of Young Children with Autism

Importance of Early Identification of Autism

It is important to identify children with ASD and begin interventions as soon as possible. Early Intervention may:



- Help children make progress in their development
- Reduce challenging behaviors and improve children's functional outcomes.
- Help families learn effective strategies to promote their children's development and manage challenging behaviors.

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 risk⁴

The prognosis for children with ASD may be greatly improved with early and intensive treatment. Early identification is critical.⁵

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)

Primary health care providers play a central role in identifying ASDs as early as possible through developmental surveillance and screening, in accordance with recommendations issued by the American Academy of Pediatrics.⁶ Signs of ASD are often difficult to elicit during the pediatric health care visit, so health care professionals must listen carefully to the observation of the parents.⁷

⁴ 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.

⁵ Hagan JF, Shaw JS, Duncan PM, eds. (2017) *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents*, 4th Edition. Elk Grove Village, IL: American Academy of Pediatrics; 2017. p130.

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

⁷ Hagan JF, Shaw JS, Duncan PM, eds. (2017) *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents*, 4th Edition. Elk Grove Village, IL: American Academy of Pediatrics; 2017. p130.

General Principles of Screening and Surveillance for Young Children

Developmental and Autism Screening

The AAP recommends that all children be screened with a standardized developmental tool at specific intervals regardless of whether a concern has been raised or a risk has been identified. There is no one developmental screening tool endorsed by the AAP as universally accepted for all populations and all ages. Many screening tools have been identified by the AAP for developmental screening.

The general developmental screening tools include:

- Ages and Stages Questionnaire (ASQ)
- Batelle Developmental Inventory Screening Tool (BDI-ST)
- Bayley Infant Neurodevelopmental Screen (BINS)
- Brigance Screening
- Child Development Inventory (CDI)
- Child Development Review-Parent Questionnaire (CDR-PQ)
- Denver-II Developmental Screening Test
- Infant Developmental Inventory
- Parents' Evaluation of Developmental Status (PEDS)

In the absence of established risk factors or parental or provider concerns, a general developmental screen is recommended at the 9, 18, and 24-month visit.

The AAP has also recommended administering an ASD-specific screening tool at the 18 and 24-month health supervision visits in addition to a general developmental screening tool.⁸

ASD screening instruments can be divided into Level 1 and Level 2. Level 1 screening instruments are autism-specific and can be used to screen all children for possible ASD. They have fewer items and take less time. Level 2 screening instruments can be used to screen children when there is already concern about possible ASD. They have more items and take more time and training to administer. These screening instruments can be used by primary care providers to decide if a child may need an evaluation by a qualified provider with expertise in diagnosing ASD.



The use of Level 1 screeners in pediatric primary health care settings is strongly recommended as part of ASD-specific early identification efforts.

The following Level 1 Screening Instruments are recommended:



- Modified Checklist for ASD in Toddlers-Revised with Follow-up (M-CHAT-R/F)
- Infant-Toddler Checklist (ITC)
- Parent Observation of Social Interaction (POSI)



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

⁸Ibid. p280.

General Principles of Screening and Surveillance for Young Children

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.

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.

It is important to consider ASD for children aged 12 to 15 months when communications concerns are identified in routine developmental surveillance.⁹

Importance and Timing of Developmental Surveillance

- Given the fact that the Centers for Disease Control and Prevention (CDC) estimates that between 1 in 40 and 1 in 59 children in the United States has an ASD, primary care providers are likely to provide care for children with ASD.¹⁰ It is important that periodic screening and ongoing developmental surveillance be accomplished routinely by primary care providers or other professionals at specific age points, starting from birth, to ensure ASD and other developmental disabilities are identified as early as possible.
- As part of periodic screening and developmental surveillance of young children, it is important to detect when developmental milestones have been missed or are delayed. It is also important to observe clinical clues and behaviors that may indicate ASD. The periodic preventive health care visits at 9, 18, and 24 months should include a general developmental screening to identify possible problems and concerns. A standardized, ASD-specific screening tool should be administered to all children at the 18-month preventive care visit and repeated at the 24-month visit.
- In addition to the healthcare provider conducting routine developmental surveillance, it is recommended that providers be very responsive any time parents bring up concerns about development or ASD by listening to concerns and conducting any additional inquiry, screening, or referral.
- **Developmental surveillance should begin at birth and occur at every preventive visit throughout childhood.¹¹**

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
- identifying the presence of risk and protective factors
- documenting the process and findings¹²
- sharing opinions and concerns with parents and other professionals who care for the child



⁹ Hagan JF, Shaw JS, Duncan PM, eds. (2017) Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, 4th Edition. Elk Grove Village, IL: American Academy of Pediatrics; 2017. p130.

¹⁰ Cited from <http://www.cdc.gov/ncbddd/autism/index.html>, accessed on December 12, 2018.

¹¹ 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.

¹² 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.

General Principles of Screening and Surveillance for Young Children

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*.¹³

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

¹³ 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.

General Principles of Screening and Surveillance for Young Children

Identifying Clinical Clues of Possible Autism

It is recommended that observation of certain ASD-related behaviors or the lack of certain age-appropriate behaviors in the social, language, and play realms be considered as clinical clues for possible ASD.

The clinical clues below are organized by age level and include speech and language delays as well as behaviors that are more specific to ASD. No single behavior is indicative of ASD on its own. Children with more general developmental delays may have a few of these symptoms. If a child has many clinical clues, parents and providers should seek an ASD-specific evaluation. The table below is not intended to be used to screen for ASD.

9-12 months	Language Delay
	Does not play with sounds or babble
	Does not localize sounds from farther away
	Does not squeal, shout, laugh, make raspberries
	Does not vocalize pleasure and displeasure
	Does not use sounds to get attention
	Does not imitate sounds or gestures spontaneously
	Social Communication
	Does not respond to his/her name
	Does not vocalize and smile when adult talks to and smiles at child
	Does not look at parents or others very much
	Does not shift gaze between people and objects
	Does not share positive and negative emotions much unless responding to sensory-motor actions or tickles
	Entertains self for a long time and does not try to get attention
	Does not respond to peek-a-boo or simple back-and-forth games
	Is not able to coordinate attention with another person for periods of time while working on activities, enjoying play and exchanging ideas
	Repetitive Behaviors/Atypical Object Interaction
	May seem much more interested in toys and watching objects than interacting with others
	Is slow to pick up what to do with toys given to him/her; does not imitate simple use of toys
	Is overly distressed by loud sounds
	Seems overly interested in the lights and sounds coming from toys or objects, such as phones

General Principles of Screening and Surveillance for Young Children

By 12-15 months	Language Delay
	Does not produce repetitive babbling (mamama, bababa) nor more complex babbling
	Does not seem to understand most common names used in household or routines (bottle, sibling or pet's name, mama, daddy)
	Social Communication
	Does not point with index finger to get another person to pay attention
	Does not start to combine eye contact, gestures, and vocalizations
	Does not monitor or look at the adult's face to see her/his reaction to things
	Repetitive Behaviors/Atypical Object Interaction
	Only does a few babyish things with toys – shakes, bangs, throws
	May love chasing, wrestling, tickling games, young version of hide and seek, but not other activities that require more social interaction

By 15-18 months onward	Language Delay
	Is not producing a few single words or imitating familiar and new actions, sounds and words (mama, dada, more, all gone, bye, cookie, up, go, etc.)
	Can't make his or her needs known through communication using words, tone of voice, word approximations
	Does not understand simple commands or statements or recognize caregiver's voice
	Social Communication
	Does not look at adult's face to see what to do next or when to take a turn
	Does not request desired things with looks, vocalizations, or gestures or shake head "no" to protest
	Does not hand objects or toys to parents to get interaction going
	Does not imitate, e.g., clap hands
	Repetitive Behaviors/Atypical Object Interaction
	Does not pick up simple pretend actions such as "talking" into a phone or putting a spoon to a toy animal or doll to "feed" it
	Does unusual actions with toys (such as spinning the wheels of toy vehicles); prefers to line objects up or stack them rather than use them in a variety of ways
	Does repetitive motor movements, such as spinning around or pacing back and forth in a pattern

General Principles of Screening and Surveillance for Young Children

By 24 months	Language Delay
	Does not have at least 50 words, is not putting two words together
	Social Communication
	Does not wave bye-bye or respond to “come give me a hug”
	Does not look at object mom is holding
	Does not draw attention to herself or himself
	Repetitive Behaviors/Atypical Object Interaction
	May favor just a few types of toys and does the same actions with them over and over again
At any time	Language Delay
	Loses words or communication skills she/he had
	Social Communication
	Suddenly or over the period of a few weeks or months stops being socially interactive, smiling, or giving eye contact

2-3 years	Language Delay
	Is not expanding number of words and sentences (expect several hundred); not comprehending multiple directions, locations, questions
	Not using language for pretend play
	Likes books but needs to control them and does not show understanding
	Social Communication
	Does not join in play with others, prefers self-directed play
	When playing with objects in presence of caregiver, doesn't give eye contact, vocalizations, smiles
	Does not engage socially with family or others
	Does not share attention or reciprocate
	Does not engage in back-and-forth social interaction with parent, caregivers, relatives, or siblings – cannot sustain a continuous flow of interactions (e.g., 5-10 back-and-forth exchanges)
	When others try to engage the child in an activity, she/he turns away, rejects it, or just ignores
	Is “hard to read” in terms of emotions shown on face
	Cannot regulate emotions, easily frustrated, tantrums, shuts down

General Principles of Screening and Surveillance for Young Children

2-3 years	Social Communication
	Instead of vocalizations or pointing, combined with eye contact, pulls the adult's hand to get what is desired
	If speech is coming in, child begins to repeat what is heard rather than use her/his own words (echoes)
	Child repeats word-for-word what characters say on a favorite video, although she/he is not using language for every-day needs (scripts)
	Puts hands on adult's hand to have them do something for the child, such as put a puzzle piece in
	May be socially indiscriminate, that is, will leave parents without concerns, will go with anyone
	May constantly try to run out the door, or away from an adult
	Repetitive Behaviors/Atypical Object Interaction
	Is particularly interested in certain topics, like naming letters and numbers, although she/he is not doing other things at age level, or can do complex puzzles past age level
	Carries an unusual object around much of the day
	Gets distressed when something happens out of order; does much better when everything is predictable
	Gets obsessed with videos and requests to watch the same one over and over
	Seeks unusual visual stimulation, such as by making things wave, flap, or spin in front of eyes, including wiggling own fingers or flapping own hand close to eye
	Finds spinning or waving things in the environment (for example, a fan) and watches for an unusually long time
	Flaps hands when excited, may combine with jumping up and down
	Toe-walks
	Has unusual responses to sensory experiences
	Touch – can't tolerate certain fabrics in clothing, can't stand certain textures on hands or feet, is overly interested in certain textures, like people's hair
	Noise – is sensitive to noise in general or to specific noises like the vacuum, food processor, garage door opening or closing, seeks out certain noises to hear over and over again
	Vision – does not like overly bright lights, seeks out certain visual experiences like things spinning, a light pattern on the wall, certain sounds or voices or music on the TV or video; loves repetitive or colorful patterns and is overly interested in watching them
	Becomes or has been extremely picky about food, may avoid textures or only eat certain textures

General Principles of Screening and Surveillance for Young Children

How can Physicians Conduct Screening and Surveillance for ASDs in their Regular Practice?¹⁴



AAP recommends incorporating screening and surveillance in the Medical Home by engaging the whole office and not only clinical staff or adding a screening tool to well-child visits.

Universal screening requires implementing front-desk procedures, such as appropriate scheduling of children's visits to include time for screening and a process to identify and flag children with risk factors. Staff may need to be trained in administering, reviewing, and scoring the developmental and ASD screening tools.

AAP recognizes that input from consumers is essential to implementing an effective system and recommends including a parent on the planning team, holding parent focus groups or administering parent questionnaires before implementing a practice-wide screening system.

The Current Procedural Terminology (CPT) code set includes codes for developmental screening (96110: developmental testing; limited) and testing (96111: developmental testing; extended). The CPT code 96110 does not include payment for medical services, and it is expected that a non-physician administers and scores the screening tool. The physician's review, interpretation and discussion of the results with the family is included in the billing code used for the well-child visit. The CPT code 96111 includes physician work and would be used when the medical provider observes the child performing a task and demonstrating a specific developmental skill. Physicians should be sure to carefully review practice processes to ensure appropriate implementation and documentation for billing and payment of developmental and ASD screening and surveillance.



¹⁴ 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.

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

AAP Surveillance and Screening Algorithm

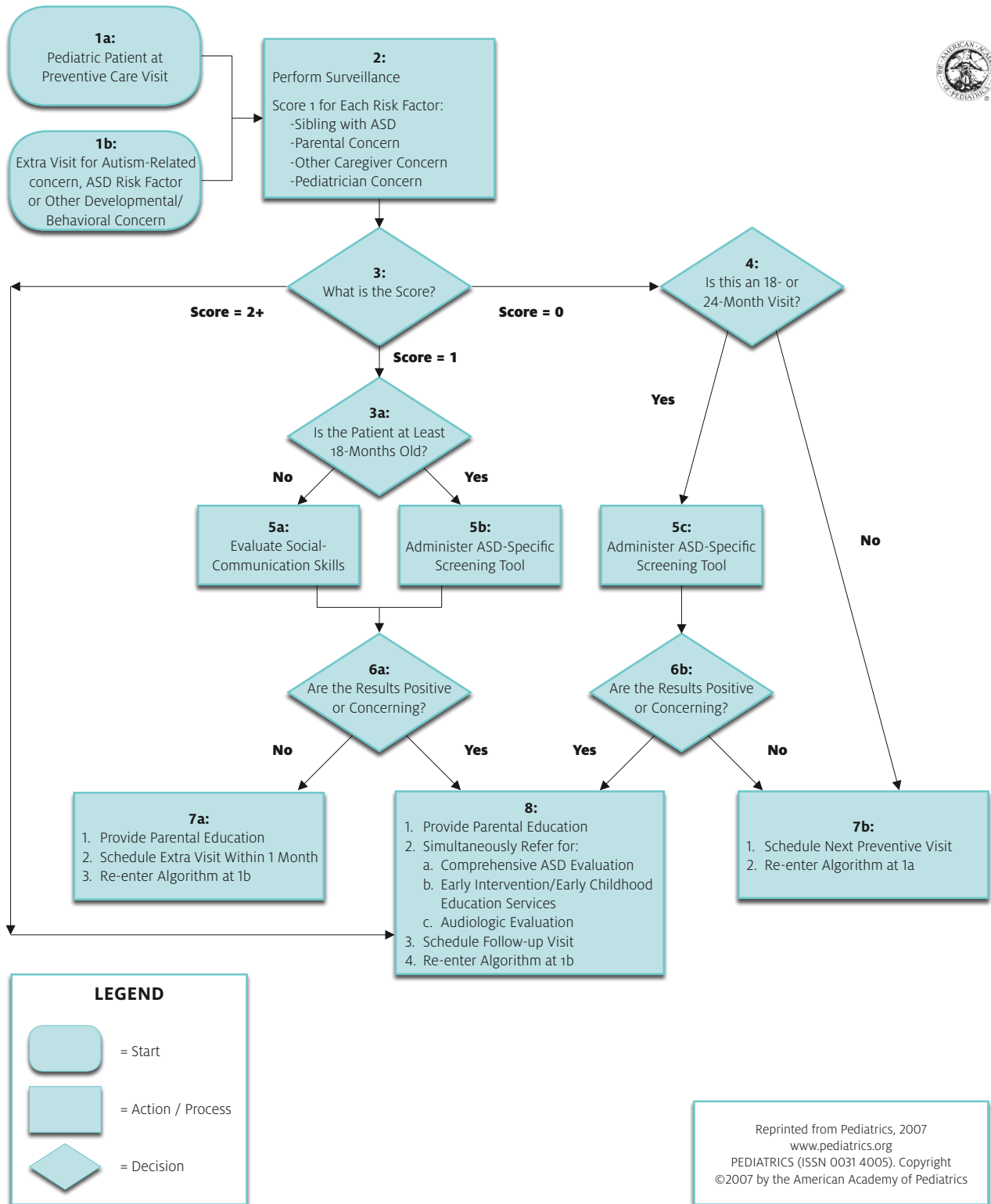


FIGURE 1
Surveillance and screening algorithm: ASDs.

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

STEP 1.¹⁵ 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 back-and-forth 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)

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.

¹⁵ 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

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 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 can 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.¹⁶

STEP 5. Screening for Autism Spectrum Disorders.

Step 5 a and b. A standardized screening tool should be administered at any point when concerns about ASD are raised by a parent or because 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.

- 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.

¹⁶American Academy of Pediatrics Policy, Identifying Infants and Young Children with Developmental Disorders in the Medical Home.

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

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 Modified Checklist for ASD in Toddlers-Revised with Follow-up (M-CHAT-R/F) is a level 1 screening tool that is available at no cost to the practitioner for use in primary care settings.
- The M-CHAT-R/F is a two-step screening tool meant to be given by primary health care providers to identify a child’s risk for an ASD. The M-CHAT-R/F, instructions, and supplemental materials are available for free download at <http://www2.gsu.edu/~psydlr>.
- The M-CHAT-R/F can be used to screen toddlers between 16 and 30 months of age. The M-CHAT-R/F 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-R/F parent completed “yes/no” questions indicate that they are at risk for ASDs, the Follow-up Parent Interview must be given by the provider. The interview can be completed in 5-15 minutes.
- The M-CHAT-R/F is simple to use and can be given by a provider with little training in ASDs.

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

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

- The M-CHAT-R/F is not intended to be used by parents to screen their own children.
- Giving the paper and pencil M-CHAT-R/F parent-completed “yes/no” questions without giving the Follow-up Parent Interview is not recommended. Results may not be accurate when the Follow-up Parent Interview is not used.
- The M-CHAT-R/F 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-R/F will be diagnosed with an ASD.
- 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.

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**.

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**.

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

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 8.2b.

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.

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, based on 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.

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

Step 8.2b. 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. For more information about the Early Intervention Program in NYS: https://www.health.ny.gov/community/infants_children/early_intervention/
- 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. For more information about preschool special education in NYS: <http://www.p12.nysed.gov/specialed/>

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 hearing 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:¹⁷

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

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

- Health, developmental, and behavioral histories that include at least a 3-generation family pedigree and a review of systems.
- Physical examination, including a thorough search for dysmorphic features and neurologic abnormalities and a Wood's lamp examination of the skin to assess for hypopigmented macules that may be indicative of Tuberous Sclerosis Complex or neurofibromatosis.
- 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.
- Determination of the presence of a DSM diagnosis, preferably with standardized tools that operationalize the DSM criteria.
- Assessment of the parents' knowledge of ASD, coping skills, and available resources.
- 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, p. 1203)

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

- Studies that should be considered for all children (for example, an audiology evaluation)
- 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)
- Targeted studies (such as EEG, metabolic studies) should be considered when specific clinical findings are identified by history or physical examination. (AAP, 2007, p. 1205)

¹⁷Plauché 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.

Recommendations from the NYSDOH Clinical Practice Guideline on Communicating Findings with Parents and other Professionals



- 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, Fifth Edition (DSM-V)*, or the most current edition of this manual.

NYSDOH Early Intervention Program

The New York State Early Intervention Program (EIP) is part of the national Early Intervention Program for infants and toddlers with disabilities and their families. First created by Congress in 1986 under the Individuals with Disabilities Education Act (IDEA), the EIP is administered by the New York State Department of Health through the Bureau of Early Intervention. In New York State, the Early Intervention Program is established in Article 25 of the Public Health Law and has been in effect since July 1, 1993.

To be eligible for services, children must be under 3 years of age and have a confirmed disability or established developmental delay, as defined by the State, in one or more of the following areas of development: physical, cognitive, communication, social-emotional, and/or adaptive.

The Early Intervention Program offers a variety of therapeutic and support services to eligible infants and toddlers with disabilities and their families, including:

- family education and counseling, home visits, and parent support groups
- special instruction
- speech pathology and audiology
- occupational therapy
- physical therapy
- psychological services
- service coordination
- nursing services
- nutrition services
- social work services
- vision services
- assistive technology devices and services

A municipal Early Intervention Official (EIO) designated by the chief elected official of the municipality/county administers the Early Intervention Program locally. Contact for the EIO is located here:

https://www.health.ny.gov/community/infants_children/early_intervention/county_eip.htm

For information about the statewide program, contact the NYS Department of Health, Bureau of Early Intervention at **(518) 473-7016** or e-mail bei@health.ny.gov.

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. For more information about preschool special education in NYS: <http://www.p12.nysed.gov/specialed/>

For information about preschool special education, email speced@nysed.gov.

