

## Special Communication | USPSTF RECOMMENDATION STATEMENT

# Screening for Autism Spectrum Disorder in Young Children

## US Preventive Services Task Force Recommendation Statement

Albert L. Siu, MD, MSPH; and the US Preventive Services Task Force (USPSTF)

**DESCRIPTION** New US Preventive Services Task Force (USPSTF) recommendation on screening for autism spectrum disorder (ASD) in young children.

**METHODS** The USPSTF reviewed the evidence on the accuracy, benefits, and potential harms of brief, formal screening instruments for ASD administered during routine primary care visits and the benefits and potential harms of early behavioral treatment for young children identified with ASD through screening.

**POPULATION** This recommendation applies to children aged 18 to 30 months who have not been diagnosed with ASD or developmental delay and for whom no concerns of ASD have been raised by parents, other caregivers, or health care professionals.

**RECOMMENDATION** The USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of screening for ASD in young children for whom no concerns of ASD have been raised by their parents or a clinician. (I statement)

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The US Preventive Services Task Force (USPSTF) makes recommendations about the effectiveness of specific preventive care services for patients without obvious related signs or symptoms.

It bases its recommendations on the evidence of both the benefits and harms of the service and an assessment of the balance. The USPSTF does not consider the costs of providing a service in this assessment.

The USPSTF recognizes that clinical decisions involve more considerations than evidence alone. Clinicians should understand the evidence but individualize decision making to the specific patient or situation. Similarly, the USPSTF notes that policy and coverage decisions involve considerations in addition to the evidence of clinical benefits and harms.

### Summary of Recommendation and Evidence

The USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of screening for autism spectrum disorder (ASD) in young children for whom no concerns of ASD have been raised by their parents or a clinician. (I statement) (Figure 1)

See the Clinical Considerations section later in this article for suggestions for practice regarding the I statement.

### Rationale

#### Importance

Autism spectrum disorder is a developmental disorder characterized by persistent and significant impairments in social interaction

and communication and restrictive and repetitive behaviors and activities, when these symptoms cannot be accounted for by another condition. In 2010, the prevalence of ASD in the United States was estimated at 14.7 cases per 1000 children, or 1 in 68 children, with substantial variability in estimates by region, sex, and race/ethnicity.<sup>1</sup>

#### Detection

The USPSTF found adequate evidence that currently available screening tests can detect ASD among children aged 18 to 30 months.

#### Benefits of Early Detection and Intervention or Treatment

The USPSTF found inadequate direct evidence on the benefits of screening for ASD in toddlers and preschool-age children for whom no concerns of ASD have been raised by family members, other caregivers, or health care professionals. There are no studies that focus on the clinical outcomes of children identified with ASD through screening. Although there are studies suggesting treatment benefit in older children identified through family, clinician, or teacher concerns, the USPSTF found inadequate evidence on the efficacy of treatment of cases of ASD detected through screening or among very young children. Treatment studies were generally very small, few were randomized trials, most included children who were older than would be identified through screening, and all were in clinically referred rather than screen-detected patients.

#### Harms of Early Detection and Intervention or Treatment

The USPSTF found that the harms of screening for ASD and subsequent interventions are likely to be small based on evidence about the prevalence, accuracy of screening, and likelihood of minimal harms from behavioral interventions.

Figure 1. US Preventive Services Task Force Grades and Levels of Certainty

What the USPSTF Grades Mean and Suggestions for Practice		
Grade	Definition	Suggestions for Practice
A	The USPSTF recommends the service. There is high certainty that the net benefit is substantial.	Offer or provide this service.
B	The USPSTF recommends the service. There is high certainty that the net benefit is moderate, or there is moderate certainty that the net benefit is moderate to substantial.	Offer or provide this service.
C	The USPSTF recommends selectively offering or providing this service to individual patients based on professional judgment and patient preferences. There is at least moderate certainty that the net benefit is small.	Offer or provide this service for selected patients depending on individual circumstances.
D	The USPSTF recommends against the service. There is moderate or high certainty that the service has no net benefit or that the harms outweigh the benefits.	Discourage the use of this service.
I statement	The USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of the service. Evidence is lacking, of poor quality, or conflicting, and the balance of benefits and harms cannot be determined.	Read the Clinical Considerations section of the USPSTF Recommendation Statement. If the service is offered, patients should understand the uncertainty about the balance of benefits and harms.

USPSTF Levels of Certainty Regarding Net Benefit	
Level of Certainty	Description
High	The available evidence usually includes consistent results from well-designed, well-conducted studies in representative primary care populations. These studies assess the effects of the preventive service on health outcomes. This conclusion is therefore unlikely to be strongly affected by the results of future studies.
Moderate	The available evidence is sufficient to determine the effects of the preventive service on health outcomes, but confidence in the estimate is constrained by such factors as the number, size, or quality of individual studies. inconsistency of findings across individual studies. limited generalizability of findings to routine primary care practice. lack of coherence in the chain of evidence. As more information becomes available, the magnitude or direction of the observed effect could change, and this change may be large enough to alter the conclusion.
Low	The available evidence is insufficient to assess effects on health outcomes. Evidence is insufficient because of the limited number or size of studies. important flaws in study design or methods. inconsistency of findings across individual studies. gaps in the chain of evidence. findings not generalizable to routine primary care practice. lack of information on important health outcomes. More information may allow estimation of effects on health outcomes.
The USPSTF defines certainty as "likelihood that the USPSTF assessment of the net benefit of a preventive service is correct." The net benefit is defined as benefit minus harm of the preventive service as implemented in a general, primary care population. The USPSTF assigns a certainty level based on the nature of the overall evidence available to assess the net benefit of a preventive service.	

**USPSTF Assessment**

The USPSTF concludes that there is insufficient evidence to assess the balance of benefits and harms of screening for ASD in children aged 18 to 30 months for whom no concerns of ASD have been raised. Evidence is lacking, of poor quality, or conflicting, and the balance of benefits and harms cannot be determined.

**Clinical Considerations**

**Patient Population Under Consideration**

This recommendation applies to children who have not been diagnosed with ASD or developmental delay and for whom no con-

cerns of ASD have been raised by parents, other caregivers, or health care professionals (Figure 2).

**Screening Tests**

A number of tests are available for screening for ASD in children younger than 30 months. The most commonly studied tool is the Modified Checklist for Autism in Toddlers (M-CHAT) and its subsequent revisions (Modified Checklist for Autism in Toddlers with Follow-Up [M-CHAT-F] and Modified Checklist for Autism in Toddlers-Revised, with Follow-Up [M-CHAT-R/F]). The M-CHAT-R/F is a parent-rated scale, and a positive finding leads to a follow-up interview. If the follow-up interview is positive, a full diagnostic workup for ASD is indicated. The screening process

Figure 2. Screening for Autism Spectrum Disorder in Young Children: Clinical Summary

Population	Children aged 18 to 30 months for whom no concerns of autism spectrum disorder (ASD) have been raised by their parents or a clinician
Recommendation	No recommendation. Grade: I (insufficient evidence)
Risk Assessment	Although a number of potential risk factors for ASD have been identified, there is insufficient evidence to determine if certain risk factors modify the performance characteristics of ASD screening tests, such as the age at which screening is performed or other characteristics of the child or family.
Screening Tests	The most commonly studied tool is the Modified Checklist for Autism in Toddlers (M-CHAT) and its subsequent revisions. A positive finding should lead to a follow-up interview, which, if positive, should lead to a full diagnostic workup for ASD.
Treatment and Interventions	Treatments for ASD include behavioral, medical, educational, speech/language, and occupational therapy and complementary and alternative medicine approaches. Treatments for young children are primarily behavioral interventions, particularly early intensive behavioral and developmental interventions.
Balance of Benefits and Harms	The USPSTF concludes that there is insufficient evidence to assess the balance of benefits and harms of screening for ASD in young children for whom no concerns of ASD have been raised.
Other Relevant USPSTF Recommendations	The USPSTF has made a recommendation on screening for speech and language delays and disorders in children 5 years or younger. This recommendation is available on the USPSTF website ( <a href="http://www.uspreventiveservicestaskforce.org">http://www.uspreventiveservicestaskforce.org</a> ).

For a summary of the evidence systematically reviewed in making this recommendation, the full recommendation statement, and supporting documents, please go to <http://www.uspreventiveservicestaskforce.org>.



assesses communication skills, joint attention, repetitive movement, and pretend play.

### Treatments and Interventions

Treatments for ASD include behavioral, medical, educational, speech/language, and occupational therapy and complementary and alternative medicine approaches. Treatments for young children in the target age group for routine screening for ASD are primarily behavioral interventions, particularly early intensive behavioral and developmental interventions, which may include approaches incorporating applied behavior analysis principles, parent training components, and play- or interaction-based interventions. Among the behavioral interventions, those based on applied behavior analysis have the highest-quality data supporting their effects on cognitive and language outcomes. These interventions can be delivered in a home or school setting and are generally time-intensive, with some programs requiring up to 40 hours a week.<sup>2</sup>

### Suggestions for Practice Regarding the I Statement

#### Potential Preventable Burden

Autism spectrum disorder can cause significant social, communication, and behavioral challenges for affected children and place substantial strain on family members and other caregivers. Treatment and maturation may reduce the effects of the core symptoms of ASD for some children, but others may experience long-term effects on education, employment, and ability to live independently.<sup>2</sup> It is important that clinicians listen carefully to parents when concerns are raised by the parents or during an examination and make prompt

use of validated tools to assess the need for further diagnostic testing and services. Disparities have been observed in the frequency and age at which ASD is diagnosed among children by race/ethnicity, socioeconomic status, and language of origin, creating concern that certain groups of children with ASD may be systematically underdiagnosed.<sup>3</sup> It is important to note that an I statement is not a recommendation for or against screening. In the absence of evidence about the balance of benefits and harms, clinicians should use their clinical judgment to decide if screening in children without overt signs and symptoms is appropriate for the population in their care.

#### Potential Harms

Although there is limited evidence about the harms of screening for ASD in children, reported potential harms include misdiagnosis and the anxiety associated with further testing after a positive screening result, particularly if confirmatory testing is delayed because of resource limitations. Behavioral treatments are not generally thought to be associated with significant harms but can place a large time and financial burden on the family. Other treatments for ASD are less well studied and were not included in this review.

#### Current Practice

A 2004 survey of pediatricians in Maryland and Delaware found that 8% screened specifically for ASD. Few data are available regarding the current prevalence of screening for ASD by clinicians in the United States.<sup>4</sup> More recent surveys have found higher rates, although they remain less than 60%.<sup>5-8</sup>

### Useful Resources

The Centers for Disease Control and Prevention provides web-based continuing education for clinicians called Autism Case Training (available at <http://www.cdc.gov/ncbddd/actearly/autism/case-modules/index.html>), as well as other information about ASD for families (available at <http://www.cdc.gov/ncbddd/autism/families.html>).

The Health Resources and Services Administration's website provides links to training resources for professionals (available at <http://mchb.hrsa.gov/programs/autism/trainingforprofessionals.html>).

The M-CHAT screening tool is available online for free at <https://m-chat.org/>. Other professional and advocacy organizations have also developed toolkits and resources.

The USPSTF has made a recommendation on screening for speech and language delays and disorders among children 5 years or younger (available at <http://www.uspreventiveservicestaskforce.org>).

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## Other Considerations

### Research Needs and Gaps

Research has focused on screening and diagnostic tools and treatment for symptomatic children, especially those who are severely affected. Good-quality studies are needed to better understand the intermediate and long-term health outcomes of screening for ASD among children without obvious signs and symptoms and whether earlier identification through universal screening is associated with clinically important improvements in health outcomes. These studies are especially needed in populations with low socioeconomic status and minority populations, where access to care may be more limited. A number of different study designs could greatly improve the understanding of the potential of screening. Large, good-quality, randomized clinical trials (RCTs) of treatment that enroll young children with ASD identified through screening and that report patient-centered outcomes are critical to understanding the effects of screening. Treatment could be compared with a wait-list control, less intense treatment, or an alternative treatment, as in the trials reviewed by the USPSTF. Similar studies in children identified through screening have recently begun to be published, indicating that this is a feasible approach.<sup>9,10</sup> Pragmatic quasi-experimental designs, such as stepped-wedge trials, in regions with low screening rates could compare the effects of screening at 18 and 24 months with later screening or case-finding on educational, behavioral, functional, and IQ measures at 6 years. Randomized clinical trials of screening may be feasible in locations where screening is not standard practice or recommended. Studies following up large samples of screen-negative children, although resource-intensive, would provide valuable information regarding screening specificity.

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## Discussion

### Burden of Disease

Autism spectrum disorder is a developmental disorder characterized by persistent and significant impairments in social interaction and communication and restrictive and repetitive behaviors and activities, when these symptoms cannot be accounted for by an

other condition. In 2010, the prevalence of ASD in the United States was estimated at 14.7 cases per 1000 children, or 1 in 68 children, with substantial variability in estimates by region, sex, and race/ethnicity.<sup>1</sup> This represents a 23% increase from 2008; the reasons for this increase are not completely understood.<sup>1</sup>

### Scope of Review

The USPSTF commissioned a systematic review<sup>2</sup> to evaluate the evidence on the accuracy, benefits, and potential harms of brief, formal screening instruments for ASD administered during routine primary care visits and the benefits and potential harms of early behavioral treatment for children identified with ASD through screening. The review focused on studies of screening in children younger than 3 years who were unselected (ie, not identified because of risk factors or concerns regarding ASD).

### Accuracy of Screening Tests

Several screening tools for ASD are available, but the strongest and most applicable evidence is for the M-CHAT/F and M-CHAT-R/F, 2 versions of the same tool. Both use a parent-rated scale that can lead to a follow-up interview, which, if positive, leads to referral for confirmatory diagnosis by a behavioral or developmental specialist. The initial screening process takes 5 to 10 minutes. Two large, good-quality trials conducted in the United States in children aged 16 to 30 months found similar positive predictive values for these tools (approximately 50%) for the detection of ASD in unselected populations.<sup>11,12</sup> The validity of these studies was weakened somewhat by the high dropout rate between screening steps but was still reasonably high for mass screening. There are no data on the specificity or negative predictive value of these screening tools. One study followed up a sample of children who were referred for diagnostic evaluation as a result of screening but not diagnosed with ASD and reported that almost all of these children had another form of developmental delay.<sup>12</sup> It is not known whether early detection of these other problems results in improved health outcomes. Although a number of potential risk factors for ASD have been identified, there is insufficient evidence to determine if certain risk factors modify the performance characteristics of ASD screening tests, such as the age at which screening is performed or other characteristics of the child or family.

### Effectiveness of Early Detection and Treatment

The USPSTF found no RCTs that directly addressed the overarching question of whether screening for ASD in children 3 years or younger results in improvements to core ASD symptoms, cognitive and intellectual functioning, language and communication skill development, challenging behavior, adaptive behavior, educational placement or achievement, or quality of life for the child and family.

The USPSTF found 26 RCTs of early intensive behavioral and developmental interventions (the most often studied treatment for this age group) for ASD in young children. However, assessment of treatment evidence was complicated by the variation among studies in intervention design, method of delivery, comparators, and outcomes measured, as well as by the heterogeneity in the age, types of symptoms, and symptom severity of the children enrolled. Four RCTs reported cognitive and language outcomes for early intensive behavioral interventions delivered by trained clinicians. Three

of the 4 trials (including the largest trial, with 294 children) reported that these interventions improved cognitive scores by 11 to 16 points (Mullen Scales of Early Learning or IQ) compared with a range of comparators (calculated from published data).<sup>13-15</sup> The fourth RCT found no effect, but this trial compared different ways of delivering the same intervention.<sup>16</sup> The same set of studies showed a similar pattern for language outcomes. Twelve RCTs of play- or interaction-based interventions reported significant improvements in some measures of interaction but not others. The other RCTs evaluated various interventions delivered by parents and found inconsistent or negative results. Studies were very small (most enrolled 20-40 children), and study quality was generally fair.

In addition to the limitations of the evidence in size, study design, and other sources of heterogeneity, it is not clear whether these studies are applicable to children who would be detected through screening. Autism spectrum disorder is a highly heterogeneous condition in terms of onset and course of core clinical ASD symptoms and cognitive and language development.<sup>17</sup> All of the treatment studies were conducted in populations of children with a previous diagnosis of ASD, many of whom were referred from specialized ASD programs. Many of the children enrolled in these studies had significant impairments in cognition, language, and behavior identified through case-finding and were older than the age group for which the screening tools were developed. Children identified through screening rather than through case-finding are likely to be younger and have milder symptoms than those in study populations. It is therefore not clear whether young children with ASD detected by screening and not because of parental or clinician concern will experience similar benefits from earlier intervention.

### Potential Harms of Screening and Treatment

The USPSTF found little evidence on the harms of screening and treatment. Potential harms include misdiagnosis and the time, effort, and anxiety associated with further testing after a positive screening result. This is of particular concern when there is a delay in confirmatory testing because of resource limitations, which are common.<sup>2</sup> Even good-quality studies of screening had a high drop-out rate between screening steps and between screening and diagnosis, suggesting that the process may be difficult for some families. Behavioral treatments are not generally thought to be associated with significant harms but can place a large time and financial burden on the family. Other treatments for ASD are less well studied and were not included in the scope of this review. The USPSTF concludes that the potential harms of screening and behavioral treatment are no greater than small.

### Estimate of Magnitude of Net Benefit

Overall, the USPSTF found insufficient evidence on screening for ASD in children aged 18 to 30 months for whom no concerns of ASD have been raised by parents, other caregivers, or health care professionals. The USPSTF identified no studies that directly evaluated the benefits or harms of screening for ASD in this age group. Studies on the benefits and harms of treatment were of small size, few were randomized, and all were conducted in populations that may not represent children who would be detected through screening programs alone. The USPSTF concludes that there is insufficient evidence to assess the balance of benefits and harms of screening for ASD in young children.

### Response to Public Comment

A draft version of this recommendation statement was posted for public comment on the USPSTF website from August 4, 2015, to August 31, 2015. Many parents of children with ASD, adults with ASD, and clinicians who care for children with ASD wrote to share their personal experiences and concerns. One major area of concern was a perception that the USPSTF was advocating against screening or against the use of screening tools to follow up on parents' concerns. This was not the USPSTF's intention, and the USPSTF will be clear when communicating this recommendation that it is not recommending for or against screening but advocating for more research. In the meantime, clinicians should use their clinical judgment, especially when caring for populations in which case-finding may be difficult because of language, access, or other barriers. Furthermore, clinicians should listen carefully to parents' concerns and use validated tools to assess whether further diagnosis or services are needed. Standardized tools, such as the M-CHAT, may be used diagnostically to follow up on concerns expressed by parents.

Another area of concern was why studies of test accuracy and the effectiveness of treatment were not sufficient to support screening and what kind of research would be needed to support a positive recommendation. In response, the USPSTF revised the recommendation statement to clarify the lack of treatment studies in the population that would likely be identified through screening and to provide greater detail about the different types of studies that could fill this evidentiary gap. Finally, other comments focused on the low cost and lack of harms associated with screening. The USPSTF revised the recommendation statement to clarify that, while the screening tools are relatively easy to administer and behavioral interventions are generally safe, the potential effects of extended treatment, in the absence of clear benefit, on families in terms of time and resources are not negligible.

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### Recommendations of Others

The American Academy of Pediatrics' Bright Futures guidelines recommend universal screening for ASD in all children at ages 18 and 24 months in addition to developmental surveillance and monitoring.<sup>17,18</sup> The American Academy of Family Physicians concludes that the current evidence is insufficient to assess the balance of benefits and harms of screening for ASD in children for whom no concerns of ASD have been raised by their parents or clinical provider.<sup>19</sup> The American Academy of Neurology and the Child Neurology Society recommend routine developmental surveillance be performed on all children to identify those at risk for any type of atypical development, followed by screening specifically for autism using one of the validated instruments (the M-CHAT or Autism Screening Questionnaire).<sup>20</sup> The American Academy of Child and Adolescent Psychiatry recommends that the developmental assessment of young children and the psychiatric assessment of all children should routinely include questions about ASD symptomatology.<sup>21</sup> The UK National Screening Committee does not recommend systematic population screening, citing concerns about the stability of ASD diagnosis at a young age, lack of data on positive predictive value, and weakness of the evidence for the efficacy of treatment.<sup>22</sup>



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