

Screening Tools for Autism in the Primary Care Setting

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Learning Objectives

- Describe effective methods for screening and early identification of children with autism spectrum disorder (ASD) in primary care.
- Report the components of diagnostic and etiologic evaluation of children with ASD.



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Autism Spectrum Disorder (ASD): Introduction

- A neurodevelopmental disorder characterized by social and communication impairment and restricted and repetitive behaviors.
- ASD is common and reported prevalence is increasing.
 - 1 in 36 children 8 years of age meet criteria for ASD.
 - 1 in 64 children 4 years of age meet criteria for ASD.
 - More than 5 million Americans in the United States have ASD.
- All pediatric clinicians can expect to have children and youth with ASD in their practice.



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Diagnosis of Autism

- Out of 1,300 families surveyed:
 - The average age of diagnosis of autism was 6 years of age, despite the fact that most parents felt something was wrong by 18 months of age
 - Less than 10% of children were diagnosed at initial presentation
 - 10% were either told to return if their worries persisted, or that their child "would grow out of it"
 - The rest were referred to another professional (at a mean age of 40 months); of which:
 - ❖ 40% were given a formal diagnosis
 - ❖ 25% were told "not to worry"
 - ❖ 25% were referred to a third or fourth professional



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Observation:
Nathan & Ben
1 Year 7 Months

GeneticsLink



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Screening and Surveillance

- Developmental screening
 - Formal process that uses standardized tests at discrete ages
- Developmental surveillance
 - An ongoing, flexible, longitudinal, and cumulative process in which health care professionals identify children who may have developmental and behavioral problems

<https://publications.aap.org/pediatrics/article/118/1/405/69580/Identifying-Infants-and-Young-Children-With-Developmental-Disorders>



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Screening and Surveillance

- General developmental screening should occur at the 9, 18, and 30 month well child visits.
- ASD specific screening should occur at the 18 and 24 month well child visits.
- Developmental surveillance should occur at every well child visit.



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Some Issues to Consider in Selecting a Tool

- Psychometrics: sensitivity/specificity should be at least 70--80%
- Time/staffing required
- Cost and reimbursement
- Parent--completed versus directly administered
- Cultural and linguistic sensitivity



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Screening Tool Comparison

Instrument	Description	Cost	Admin time	Psychometrics	Literacy Language issues
M-CHAT-R	Use 16-48 months 23 items	Free (in public domain)	5-10 minutes Parent	Sens: .85-.87 (mod) Spec: .93-.99 (high)	? Reading level English, Spanish, Turkish, Chinese, Japanese
PDDST-II PSC	Use 18-48 months 22 items	\$149/kit \$42/25 response forms	10-15 minutes Parent	Sens: .85-.92 (mod-high) Spec: .71-.91 (mod-high)	? Reading level English



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Screening and Surveillance

- The AAP does not support or endorse the use of any developmental screening tool over another.
 - Examples are provided in the ASD clinical report and AAP STAR Center website.
- Results of screening tests are not diagnostic.
 - Children identified at risk through screening and surveillance should have a diagnostic evaluation.
- Early identification and intervention can and does influence outcomes.
 - Children should be referred for developmental intervention as soon as the need becomes apparent and not wait for ASD diagnostic evaluation to take place.



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From: Promoting Optimal Development: Identifying Infants and Young Children With Developmental Disorders Through Developmental Surveillance and Screening

Pediatrics. 2020;145(1). doi:10.1542/peds.2019-3449

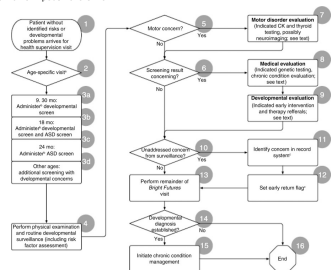


Figure Legend:
Algorithm for screening a patient without identified risks for developmental problems at a health supervision visit. Numbers and headings refer to steps in the algorithm. *To identify problems not previously recognized during earlier screenings, clinicians should pay particular attention to developmental surveillance at the age 4- or 5-year visit, before entering kindergarten. Developmental surveillance should continue throughout childhood. †Screening instruments may be administered through a previsit process initiated by the practice or by the family. ‡Providers should create methods in their record system (paper or electronic) to ensure that these facts are visible to clinicians in future visits and in the previsit process. CK, creatine kinase.

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Barriers to Early Identification of ASD

- Milder symptoms
- Average range intelligence
- Boys identified more frequently than girls (4:1)
- Co-existing conditions like attention-deficit/hyperactivity disorder (ADHD)
- Race, ethnicity, socioeconomic factors
- Culturally sensitive screening measures



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Case reports

- While seeing patients at a community clinic, you meet with Matthew...
 - 18-month-old for WCC
 - Very few words-parents think because he is bilingual
- Your next patient is Claudia
 - 2-year-old who just moved into town
 - Very few words-stares at the door



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Case reports

- What stands out to you about Matthew and Claudia?
- Matthew's and Claudia's caregivers complete the M-CHAT-R questionnaire



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Case Reports

- Please score Matthew and/or Claudia's M-CHAT forms



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M-CHAT-R™ **MATTHEW**

Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer no. Please circle yes or no for every question. Thank you very much.

- If you point at something across the room, does your child look at it? ☒ Yes ☐ No
- Have you ever wondered if your child might be deaf? ☒ Yes ☐ No
- Does your child play pretend or make-believe? (For EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?) ☒ Yes ☐ No
- Does your child like climbing on things? (For EXAMPLE, furniture, playground equipment, or stairs) ☒ Yes ☐ No
- Does your child make unusual finger movements near his or her eyes? (For EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?) ☒ Yes ☐ No
- Does your child point with one finger to ask for something or to get help? (For EXAMPLE, pointing to a snack or toy that is out of reach?) ☒ Yes ☐ No
- Does your child point with one finger to show you something interesting? (For EXAMPLE, pointing to an airplane in the sky or a big truck in the road) ☒ Yes ☐ No
- Is your child interested in other children? (For EXAMPLE, does your child watch other children, smile at them, or go to them?) ☒ Yes ☐ No
- Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (For EXAMPLE, showing you a flower, a stuffed animal, or a toy truck) ☒ Yes ☐ No
- Does your child respond when you call his or her name? (For EXAMPLE, does he or she look up, look at bottles, or stop what he or she is doing when you call his or her name?) ☒ Yes ☐ No
- When you smile at your child, does he or she smile back at you? ☒ Yes ☐ No
- Does your child get upset by everyday noises? (For EXAMPLE, does your child scream or cry to noise such as a vacuum cleaner or loud music?) ☒ Yes ☐ No
- Does your child walk? ☒ Yes ☐ No
- Does your child look you in the eye when you are talking to him or her, playing with him or her, or sharing him or her? ☒ Yes ☐ No
- Does your child try to copy what you do? (For EXAMPLE, wave bye-bye, clap, or make a funny noise when you do) ☒ Yes ☐ No
- If you turn your head to look at something, does your child look around to see what you are looking at? ☒ Yes ☐ No
- Does your child try to get you to watch him or her? (For EXAMPLE, does your child look at you for praise, or say "look" or "watch me"?) ☒ Yes ☐ No
- Does your child understand when you tell him or her to do something? (For EXAMPLE, if you don't point, can your child understand "put the book on the shelf" or "bring me the blanket"?) ☒ Yes ☐ No
- If something new happens, does your child look at your face to see how you feel about it? (For EXAMPLE, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?) ☒ Yes ☐ No
- Does your child like movement activities? (For EXAMPLE, being swung or bounced on your knee) ☒ Yes ☐ No

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M-CHAT-R™ **CLAUDIA**

Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer no. Please circle yes or no for every question. Thank you very much.

- If you point at something across the room, does your child look at it? ☒ Yes ☐ No
- Have you ever wondered if your child might be deaf? ☒ Yes ☐ No
- Does your child play pretend or make-believe? (For EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?) ☒ Yes ☐ No
- Does your child like climbing on things? (For EXAMPLE, furniture, playground equipment, or stairs) ☒ Yes ☐ No
- Does your child make unusual finger movements near his or her eyes? (For EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?) ☒ Yes ☐ No
- Does your child point with one finger to ask for something or to get help? (For EXAMPLE, pointing to a snack or toy that is out of reach?) ☒ Yes ☐ No
- Does your child point with one finger to show you something interesting? (For EXAMPLE, pointing to an airplane in the sky or a big truck in the road) ☒ Yes ☐ No
- Is your child interested in other children? (For EXAMPLE, does your child watch other children, smile at them, or go to them?) ☒ Yes ☐ No
- Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (For EXAMPLE, showing you a flower, a stuffed animal, or a toy truck) ☒ Yes ☐ No
- Does your child respond when you call his or her name? (For EXAMPLE, does he or she look up, look at bottles, or stop what he or she is doing when you call his or her name?) ☒ Yes ☐ No
- When you smile at your child, does he or she smile back at you? ☒ Yes ☐ No
- Does your child get upset by everyday noises? (For EXAMPLE, does your child scream or cry to noise such as a vacuum cleaner or loud music?) ☒ Yes ☐ No
- Does your child walk? ☒ Yes ☐ No
- Does your child look you in the eye when you are talking to him or her, playing with him or her, or sharing him or her? ☒ Yes ☐ No
- Does your child try to copy what you do? (For EXAMPLE, wave bye-bye, clap, or make a funny noise when you do) ☒ Yes ☐ No
- If you turn your head to look at something, does your child look around to see what you are looking at? ☒ Yes ☐ No
- Does your child try to get you to watch him or her? (For EXAMPLE, does your child look at you for praise, or say "look" or "watch me"?) ☒ Yes ☐ No
- Does your child understand when you tell him or her to do something? (For EXAMPLE, if you don't point, can your child understand "put the book on the shelf" or "bring me the blanket"?) ☒ Yes ☐ No
- If something new happens, does your child look at your face to see how you feel about it? (For EXAMPLE, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?) ☒ Yes ☐ No
- Does your child like movement activities? (For EXAMPLE, being swung or bounced on your knee) ☒ Yes ☐ No

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Scoring of MCHAT-R

- For most items, YES is a typical response, and NO is an at-risk response. HOWEVER, items 2, 5, and 12 are reverse scored, meaning that NO is a typical response and YES is an at-risk response. To score the M-CHAT-R, add up the number of at-risk responses, and follow the algorithm below.
- Total Score 0-2:** The score is LOW risk. No Follow-Up needed. Child has screened negative. Rescreen at 24 months if the child is younger than 2 years old (or after 3 months has elapsed), and refer as needed if developmental surveillance or other tools suggest risk for ASD.
- Total Score 3-7:** The score is MODERATE risk. Administer the M-CHAT-R Follow-Up items that correspond to the at-risk responses. Only those items which were scored at risk need to be completed. If 2 or more items continue to be at-risk, refer the child immediately for (a) early intervention and (b) diagnostic evaluation.
- Total Score: 8-20:** The score is HIGH risk. It is not necessary to complete the M-CHAT-R Follow-Up at this time. Bypass Follow-Up, and refer immediately for (a) early intervention and (b) diagnostic evaluation.



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M-CHAT-R Follow-Up™ Scoring Sheet

Please note: Yes/No has been replaced with Pass/Fail

- If you point at something across the room, does your child look at it? **Pass** **Fail**
(FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?)
- Have you ever wondered if your child might be deaf? **Pass** **Fail**
(FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?)
- Does your child play pretend or make-believe? **Pass** **Fail**
(FOR EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal)
- Does your child like climbing on things? **Pass** **Fail**
(FOR EXAMPLE, furniture, playground equipment, or stairs)
- Does your child make unusual finger movements near his or her eyes? **Pass** **Fail**
(FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?)
- Does your child point with one finger to ask for something or to get help? **Pass** **Fail**
(FOR EXAMPLE, pointing to a snack or toy that is out of reach)
- Does your child point with one finger to show you something interesting? **Pass** **Fail**
(FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road)
- Is your child interested in other children? **Pass** **Fail**
(FOR EXAMPLE, does your child watch other children, smile at them, or go to them?)
- Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? **Pass** **Fail**
(FOR EXAMPLE, showing you a flower, a stuffed animal, or a toy truck)
- Does your child respond when you call his or her name? **Pass** **Fail**
(FOR EXAMPLE, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)
- When you smile at your child, does he or she smile back at you? **Pass** **Fail**
- Does your child get upset by everyday noises? **Pass** **Fail**
(FOR EXAMPLE, a vacuum cleaner or loud music)
- Does your child walk? **Pass** **Fail**
- Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her? **Pass** **Fail**
- Does your child try to copy what you do? **Pass** **Fail**
(FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do)
- If you turn your head to look at something, does your child look around to see what you are looking at? **Pass** **Fail**
- Does your child try to get you to watch him or her? **Pass** **Fail**
(FOR EXAMPLE, does your child look at you for praise, or say "look" or "watch me")
- Does your child understand when you tell him or her to do something? **Pass** **Fail**
(FOR EXAMPLE, if he or she hears a stranger or funny noise, or sees a new toy, will he or she look at the face?)
- If something new happens, does your child look at your face to see how you feel about it? **Pass** **Fail**
(FOR EXAMPLE, if he or she hears a stranger or funny noise, or sees a new toy, will he or she look at the face?)
- Does your child like movement activities? **Pass** **Fail**
(FOR EXAMPLE, being swung or bounced on your knee)



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M-CHAT-R Follow-Up™ Scoring Sheet

Please note: Yes/No has been replaced with Pass/Fail

MATTHEW

- If you point at something across the room, does your child look at it? **Pass** **Fail**
(FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?)
- Have you ever wondered if your child might be deaf? **Pass** **Fail**
(FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?)
- Does your child play pretend or make-believe? **Pass** **Fail**
(FOR EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal)
- Does your child like climbing on things? **Pass** **Fail**
(FOR EXAMPLE, furniture, playground equipment, or stairs)
- Does your child make unusual finger movements near his or her eyes? **Pass** **Fail**
(FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?)
- Does your child point with one finger to ask for something or to get help? **Pass** **Fail**
(FOR EXAMPLE, pointing to a snack or toy that is out of reach)
- Does your child point with one finger to show you something interesting? **Pass** **Fail**
(FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road)
- Is your child interested in other children? **Pass** **Fail**
(FOR EXAMPLE, does your child watch other children, smile at them, or go to them?)
- Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? **Pass** **Fail**
(FOR EXAMPLE, showing you a flower, a stuffed animal, or a toy truck)
- Does your child respond when you call his or her name? **Pass** **Fail**
(FOR EXAMPLE, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)
- When you smile at your child, does he or she smile back at you? **Pass** **Fail**
- Does your child get upset by everyday noises? **Pass** **Fail**
(FOR EXAMPLE, a vacuum cleaner or loud music)
- Does your child walk? **Pass** **Fail**
- Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her? **Pass** **Fail**
(FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do)
- Does your child try to copy what you do? **Pass** **Fail**
(FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do)
- If you turn your head to look at something, does your child look around to see what you are looking at? **Pass** **Fail**
- Does your child try to get you to watch him or her? **Pass** **Fail**
(FOR EXAMPLE, does your child look at you for praise, or say "look" or "watch me")
- Does your child understand when you tell him or her to do something? **Pass** **Fail**
(FOR EXAMPLE, if you don't point, can your child understand "put the book on the chair" or "bring me the blanket")
- If something new happens, does your child look at your face to see how you feel about it? **Pass** **Fail**
(FOR EXAMPLE, if he or she hears a stranger or funny noise, or sees a new toy, will he or she look at the face?)
- Does your child like movement activities? **Pass** **Fail**
(FOR EXAMPLE, being swung or bounced on your knee)



Matthew, score negative on Follow-Up because he does not all 2 items

Total Score: 0

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M-CHAT-R Follow-Up™ Scoring Sheet **CLAUDIA**

Please note: **Yes/No** has been replaced with **Pass/Fail**

1. If you point at something across the room, does your child look at it? (For Example, if you point at a toy or an animal, does your child look at the toy or animal?)	Pass	Fail
2. Have you ever wondered if your child might be deaf? (For Example, does your child wiggle his or her fingers close to his or her eyes?)	Pass	Fail
3. Does your child play pretend or make-believe? (For Example, pretend to drive from an empty box, pretend to talk on a phone, or pretend to feed a doll or stuffed animal)	Pass	Fail
4. Does your child like climbing on things? (For Example, furniture, playground equipment, or stairs)	Pass	Fail
5. Does your child make unusual finger movements near his or her eyes? (For Example, does your child wiggle his or her fingers close to his or her eyes?)	Pass	Fail
6. Does your child point with one finger to ask for something or to get help? (For Example, pointing to a snack or toy that is out of reach)	Pass	Fail
7. Does your child point with one finger to show you something interesting? (For Example, pointing to an airplane in the sky or a big truck in the road)	Pass	Fail
8. Is your child interested in other children? (For Example, does your child watch other children, smile at them, or go to them?)	Pass	Fail
9. Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (For Example, showing you a flower, a stuffed animal, or a toy truck)	Pass	Fail
10. Does your child respond when you call his or her name? (For Example, does he or she turn to look or listen, or stop what he or she is doing when you call his or her name?)	Pass	Fail
11. When you smile at your child, does he or she smile back at you?	Pass	Fail
12. Does your child get upset by everyday noises? (For Example, vacuum cleaner or loud music)	Pass	Fail
13. Does your child walk?	Pass	Fail
14. Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her? (For Example, does he or she look up, talk to babies, or stop what he or she is doing when you call his or her name?)	Pass	Fail
15. Does your child try to copy what you do? (For Example, wave her/his, clap, or make a funny noise when you do)	Pass	Fail
16. If you turn your head to look at something, does your child look around to see what you are looking at?	Pass	Fail
17. Does your child try to get you to watch him or her? (For Example, does your child look at you to praise, or say "look" or "watch me")	Pass	Fail
18. Does your child understand when you tell him or her to do something? (For Example, if you don't want your child to understand "put the book on the chair" or "bring me the blanket")	Pass	Fail
19. If something new happens, does your child look at your face to see how you feel about it? (For Example, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?)	Pass	Fail
20. Does your child like movement activities? (For Example, being swung or bounced on your knee)	Pass	Fail

Claudia screens positive on Follow-Up because she fails 7 items or more.

Total Score: 10

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3. Does **CLAUDIA** play pretend or make-believe

Yes

Please give me an example of how he/she plays pretend (If parent does not give a PASS example below, ask each individually)

Does he/she ever...

Pretend to drink from a toy cup?	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
Pretend to eat from a toy spoon or fork?	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
Pretend to talk on the telephone?	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
Pretend to feed a doll or stuffed animal with real or imaginary food?	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
Push a car as if it is going along a pretend road?	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
Pretend to be a robot, an airplane, a ballerina, or any other favorite character?	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
Put a toy pet in a pretend house?	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
Put an action figure or doll into a car or truck as if it is the driver or passenger?	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
Pretend to vacuum the rug, sweep the floor, or the move lanes?	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
Other (describe):	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>

No ☒

Yes to any

PASS

No to all ☒

FAIL

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Case reports

- What would you do next?

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Summary/Take Home Points

- ASD is a common neurodevelopmental disability that significantly impacts the lives of youth and families.
- Autism and general developmental screening can be done in a primary care setting at a well child visit.
- Screening does not mean diagnosis.
- Early identification and intervention improves outcomes.



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Resources: AAP Policy

- Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening <https://publications.aap.org/pediatrics/article/118/1/405/69580/Identifying-Infants-and-Young-Children-With>
- Identification, Evaluation, and Management of Children With Autism Spectrum Disorder <https://pediatrics.aappublications.org/content/145/1/e20193447>
- Executive Summary: Identification, Evaluation, and Management of Children With Autism Spectrum Disorder <https://pediatrics.aappublications.org/content/145/1/e20193448>
- Promoting Optimal Development: Identifying Infants and Young Children With Developmental Disorders Through Developmental Surveillance and Screening <https://pediatrics.aappublications.org/content/145/1/e20193449>



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Resources: AAP Tools

- www.aap.org/autism
 - *Caring for Children with Autism Spectrum Disorder: A Practical Resource Toolkit for Clinicians*, 3rd Edition <https://toolkitsolutions.aap.org/autism/home>
 - *Autism Spectrum Disorder: What Every Parent Needs to Know*, 2nd Edition <https://shop.aap.org/autism-spectrum-disorder-paperback>
 - HealthyChildren.org ASD articles for families/caregivers www.healthychildren.org/English/health-issues/conditions/Autism/Pages/default.aspx
- Bright Futures National Center <https://brightfutures.aap.org/Pages/default.aspx>
- National Resource Center for Patient/Family-Centered Medical Home <https://medicalhomeinfo.aap.org/Pages/default.aspx>
- Screening in Practices Initiative www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Screening/Pages/default.aspx



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Resources: Other Organizations

- Family-to-Family Health Information Centers
<https://familyvoices.org/lfpp/f2fs>
- Centers for Disease Control and Prevention
 - Autism and Developmental Disabilities Monitoring Network
www.cdc.gov/ncbddd/autism/addm.html
 - Learn the Signs. Act Early. www.cdc.gov/ncbddd/actearly/index.html
- Autism Treatment Network Toolkits
<https://airpnetwork.org/what-we-do/toolkits>
- Title V Children and Youth with Special Health Care Needs Programs
www.amchp.org/Policy-Advocacy/MCHAdvocacy/Pages/StateProfiles.aspx
- Association of University Centers on Disabilities
www.aucd.org/template/index.cfm

