**Prepared for:**

**The Office of the National Coordinator for Health Information Technology (ONC) and The Substance Abuse and Mental Health Services Administration (SAMHSA)**

# ONC-SAMHSA Behavioral Health Clinical Quality Measure Initiative

## Technical Expert Panel Results for Behavioral Health Domain – *Autism*

**September 26, 2012**

**by The Mitre Corporation**

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# Executive Summary

## Background

The Office of the National Coordinator for Health Information Technology (ONC) and the Substance Abuse and Mental Health Services Administration (SAMHSA) engaged The MITRE Corporation to support the development of a portfolio of Behavioral Health (BH) Clinical Quality Measures (CQMs). This portfolio of BH CQMs are under consideration for future stages of the Centers for Medicare & Medicaid Services (CMS) Incentive Program for the Meaningful Use of Health Information Technology ("Meaningful Use"), which is part of the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009. This engagement is comprised of two phases:

1. Electronic specification (eSpecification) of prioritized BH CQMs under consideration for future stages of the Meaningful Use (MU) program
2. Development and facilitation of a Technical Expert Panel (TEP) of public and private BH specialists for the purpose of identifying and prioritizing recommendations for future development of BH related CQMs

This report presents results of the BH CQM Project Phase 2 effort for the Autism BH domain.

## Process

A TEP composed of public and private sector BH experts, representing the clinical domains of Alcohol Use, Autism, Depression, Drug Use, Suicide, and Trauma, was recruited, assembled, and facilitated over a 4-month period named "TEP Phase 1" from April through July 2012. Through the course of deliberations, the TEP was briefed on the MU program requirements and informed of the CQM development process, including clinical research, measure logic development, National Quality Forum (NQF) endorsement, and eSpecification creation. In a three-meeting weekly rotating cycle, each clinical domain was evaluated for the existence of CQMs included in the MU Stage 1 Final Rule, the MU Stage 2 Notice of Proposed Rulemaking (NPRM) and MU Stage 2 Final Rule, and those eSpecified as part of Project Phase 1. Additionally, the TEP reviewed results of environmental scans for the existence of measures not endorsed by the NQF and clinical literature searches for evidence warranting new measure development.

A "TEP Phase 2" will focus for an additional three months of July through September 2012, on the topics of Depression Trended Outcome measurement and Drug Use/Prescription Drug Misuse measures.

## Results

Table 1 provides an overview of the ONC-SAMHSA BH TEP's research activities and recommendations related to developing BH CQMs for the Autistic Spectrum Disorder or "Autism" domain.

Table 1. Behavioral Health Domain: *Autism*

| Source | Result |
|---|---|
| Domain specific NQF endorsed measures | Two measures were prioritized from Phase 1 of the BH CQM project |
| Meaningful Use Stage 1-Final Rule | No measures identified for this clinical domain |
| Meaningful Use Stage 2-Final Rule | No measures identified for this clinical domain |
| NQF endorsed measures – future consideration | Two measures identified that could be applied to this domain |
| Non-endorsed Measures (Agency for Healthcare Research and Quality [AHRQ] Database) | Five measures related to this clinical domain were reviewed by TEP, none were recommended |
| Clinical Evidence | 181 citations identified for this clinical domain and categorized by broad topic areas:*<br>• Universal Versus Selective Screening<br>• Screening Measures—Psychometric Properties<br>• Provider and Implementation Studies<br>• Screening Frequency<br>• Age to Start/Studies Under Age 2<br>• Referral Practices<br>• Tracking Outcomes<br>• Treatment<br>• Biomarkers/Genetics<br>• Comorbidities, Medical Conditions, Differential Diagnosis<br>• Electronic Health Records<br>• General Reviews |

* Citations were repeated when findings applied to more than one topic area.

## Recommendations

Based on the TEP's findings, the Autism subgroup recommends:

- Further enhancement of clinical quality measure NQF 1399, Developmental screening by 2 years of age, to leverage for development of an Autism-specific screening
- Development of a CQM for universal screening or a suite of screenings of Autism appropriate for diagnosing the disorder across the life span

The following report provides details concerning the ONC-SAMHSA BH TEP activities and recommendations for the Autism BH clinical domain.

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# 1 Background

Through the American Recovery and Reinvestment Act of 2009 (ARRA) Health Information Technology for Economic and Clinical Health (HITECH) Act, the Centers for Medicare & Medicaid Services (CMS) is authorized to provide reimbursement incentives for eligible professionals and hospitals for the Meaningful Use (MU) of certified Electronic Health Record (EHR) technology. The Office of the National Coordinator for Health Information Technology (ONC), through an agreement with CMS, has been tasked with developing a portfolio of Clinical Quality Measures (CQM) that capitalizes on the clinical data captured through EHRs for inclusion in the CMS EHR MU Incentive Program.

The Behavioral Health Coordinating Committee at the U.S. Department of Health and Human Services (DHHS), with support from the Office of National Drug Control Policy (ONDCP) Demand Reduction Interagency Workgroup EHR subcommittee, submitted consensus recommendations to the ONC, for behavioral health-relevant clinical quality measures to be included in Stage 2 of the MU incentive program. In July 2011, the ONC Federal Advisory Health Information Technology Policy Committee (HITPC) recommended to ONC that these measures be further developed.

SAMHSA and ONC jointly sponsored this project to follow up on these recommendations by developing and electronically specifying (eSpecification) BH CQMs to be added to the current EHR CQM portfolio of measures. The principal audience for these measures is primary care MU Eligible Professionals and Eligible Hospitals, although they may also be applicable to a broader range of BH professionals. The scope of the resulting BH eMeasure (BHeM) effort included strategic, technical, facilitation, coordination, clinical, and project management support for the development of a portfolio of electronically specified BH CQMs for potential inclusion in future stages of the CMS EHR MU Incentive Program.

BH CQMs for this project are focused in the clinical domains of:

- Alcohol Use
- Autism
- Depression
- Drug Use
- Suicide
- Trauma

This report presents results of the BH CQM Project Phase 2 Technical Expert Panel (TEP) effort for the Autism BH domain.

# 2 Project Overview

The ONC and SAMHSA engaged The MITRE Corporation to support the development of a portfolio of BH CQMs suitable for inclusion in future stages of the CMS Incentive Program for the Meaningful Use of Health Information Technology (“Meaningful Use”), which is part of the Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH). This engagement included two phases:

**Phase 1** - eSpecification of BH CQMs suitable for future stages of the MU program. 10 BH CQMs were eSpecified through this project and include:

- National Committee for Quality Assurance (NCQA)
  1. NQF #0576, Follow-Up After Hospitalization for Mental Illness
  2. NQF #1401, Maternal Depression Screening
  3. NQF #1406, Risky Behavior Assessment or Counseling by Age 13
  4. NQF #1507, Risky Behavior Assessment or Counseling by Age 18
- The Joint Commission (TJC):
  5. NQF #1661, SUB-1 Alcohol Use Screening
  6. NQF #1663, SUB-2 Alcohol Use Brief Intervention Provided
- Center for Quality Assessment and Improvement in Mental Health (CQAIMH):
  7. NQF #0109, Bipolar Disorder and Major Depression: Assessment for Manic or Hypomanic Behaviors
  8. NQF#0110, Bipolar Disorder and Major Depression: Appraisal for Alcohol or Chemical Substance Use
  9. NQF #0111, Bipolar Disorder: Appraisal for Risk of Suicide
- Resolution Health, Inc. (RHI)
  10. NQF # 0580, Bipolar Antimanic Agent

Note: CQMs NQF #0110 and #1401 were included in MU Stage 2 Final Rule

**Phase 2** - Development and facilitation of a TEP of public and private BH specialists for the purpose of identifying and prioritizing recommendations for potential new measures for future development.

## 2.1 Technical Expert Panel

A TEP composed of public and private sector BH experts, representing the clinical domains of Alcohol Use, Autism, Depression, Drug Use, Suicide, and Trauma, was recruited, assembled, and facilitated over a 4-month period named "TEP Phase 1" from April through July 2012. Through the course of deliberations, the TEP was briefed on the MU program requirements and informed of the CQM development process, including clinical research, measure logic development, National Quality Forum (NQF) endorsement, and eSpecification creation. In a three-meeting weekly rotating cycle, each clinical domain was evaluated for the existence of CQMs included in the MU Stage 1 Final Rule, the MU Stage 2 Notice of Proposed Rulemaking (NPRM), and those eSpecified as part of Project Phase 1. Additionally, the TEP reviewed results of environmental scans for the existence of measures not endorsed by the NQF and clinical literature searches for evidence warranting measure development.

A "TEP Phase 2" focused for an additional three months from July through September 2012 on the topics of Depression Trended Outcome and Drug Use/Prescription Drug Misuse measures.

A list of all TEP members is included in Appendix A.

## 2.2 Purpose and Activities of the TEP

The purpose of the ONC-SAMHSA BH TEP was to:

- Recommend BH clinical quality measures for widespread adoption and use in future stages of the EHR Meaningful Use Incentive Program
- Recommend future measure development needs by evaluating available clinical research
- Provide private sector input regarding the feasibility of measure implementation

Over the course of the project the TEP completed a comprehensive review of existing BH-relevant CQMs including measures that are NQF endorsed, community measures in the AHRQ measure clearinghouse, and measures that were under development through similar federal initiatives. In addition, for each domain, the TEP reviewed the clinical literature to evaluate the state of the field of measure development and to make recommendations on the next steps for measure development.

A list of all scheduled meetings and topics is included in Appendix B.

Copies of the environmental scans are included in Appendix C.

SAMHSA is currently developing a National Behavioral Health Quality Framework. The framework is aligned with the National Quality Strategy and will prioritize six goals; (1) evidence-based prevention, treatment and recovery, (2) person and family-centered care, (3) coordination of behavioral health and other health care, (4) health living, (5) safe care, and (6) accessible and affordable care. The recommendations from the Technical Expert Panel are focused on measure recommendations for the Meaningful Use EHR incentive program and are primarily applicable to primary care and general hospital settings. These recommendations will be considered in the broad portfolio of SAMHSA quality work, including development of the framework and future measure development activities.

## 2.3 Common Themes in CQM Development for Behavioral Health

Many common themes emerged in the TEP discussions across the six domains. The United States (US) healthcare system is evolving rapidly. The widespread use of standardized data captured in EHRs has profound potential to improve quality measurement in both research and healthcare contexts. Our discussions highlighted some principles related to BH quality measures development for consideration in efforts to realize this potential.

### Standardized, Validated Screening and Assessment Tools

Significant discussion focused on the use of valid tools for screening, assessment, and outcome monitoring for BH diagnoses. Many standardized assessment tools exist for any given BH condition. There is often no ‘gold standard’ assessment tool for a given purpose. As a result, measure developers often specify the use of ‘a valid instrument’. This can create complications for the e-specification of the measure and for data comparison across sites. However, while standards may be useful for exchanging data, mandating the use of a specific instrument may limit a provider’s ability to select tools that they prefer, or develop new, innovative approaches to screening and assessment. Development of standards for the endorsement of validated tools, as well as standard processes for calibrating tools to a standard scale would be incredibly

valuable for improving the quality and interoperability of data while allowing the field to evolve with the state of the science.

### Comprehensive Measure Sets

For each of the six domains TEP members discussed the long range goal of developing measure sets that support evidence based practices across the full continuum of care. For most BH disorders addressed in primary care settings this includes prevention, screening, follow up assessments, screening for co-morbid conditions, primary care based intervention, referral management, care coordination, and outcome tracking. For many of the domains addressed in this project the state of the research does not yet support the development of CQMs for each of these purposes. However, it was useful to consider the current state of measure development within this context to make recommendations for the next stages of measure development.

### Implementation in Real World Settings

TEP discussions also highlighted the need to consider measure development in the context of real world healthcare settings. Our national healthcare system is rapidly evolving and health reform is putting significant pressure on primary care providers. The efficacy of primary care based interventions for behavioral disorders is highly dependent on implementation which can be influenced by acceptability to providers, ability to integrate best practices into their workflow, provider attitudes and comfort level with the intervention, etc. The TEP highlighted the need for additional research to address the implementation barriers that exist in busy practices, including technologies that reduce patient and provider burden, to identify methods for addressing patients with multiple behavioral health co-morbidities, and to determine how clinical decision support can be tied to CQMs in EHR systems.

# 3 Domain-Specific Results: *Autism*

## 3.1 Environmental Scan Results

MITRE engaged The Cloudburst Group as the subcontractor for the clinical literature review process based on their expertise in completing and analyzing clinical literature research in the six key domains of Alcohol, Substance Abuse, Depression, Suicide, Trauma and Autism. The Cloudburst Group deliverables were aligned with the goals of each TEP meeting (see Table 2).

Table 2. TEP Goals and Literature Reviews

| TEP Phase 1 – Goal (all 6 Domains) | Literature Review Deliverables |
|---|---|
| Meeting 1 - Orientation and Familiarity with Current Measures | TEP participation and orientation if available |
| Meeting 2 - Non-Endorsed Measures Recommendations/Lit Search Question Formation | Delivery of Phase 1 environmental scan literature review domain-specific search questions for all 6 domains and participation in weekly TEPs |
| Meeting 3 - Select Promising Clinical Research | Delivery of final results from Phase 1 environmental scan of all 6 domains and participation in weekly TEPs |

The Cloudburst Group provided literature search questions for review with the TEP at each domain Phase 1, Meeting 2 discussion. These questions were based on a preliminary review of ongoing research that could inform the development or retooling of each proposed measure or the creation of new measures. The answers to these questions and additional comments from the TEP members in the Meeting 2 discussions were used to generate the search criteria for the environmental scans. The results of these scans were then summarized and presented to each TEP in an executive summary (Table 3). The most appropriate articles were then collated for each domain and presented in a literature matrix (see Appendix C).

### Recommended Search Terms for Autism Literature Scan:

- Autism, screening
- Autism, broadband
- Autism, primary care, referral
- Autism, primary care, guidelines
- Autism, referral, treatment
- Autism, measures, psychometric

Below is a high-level summary of the 181 total results divided under 4 broad areas. The full matrix including summaries of each of the citations is available in Appendix C of this paper.

Table 3. Literature Search Results and Findings

| Topics/Search Focus Area | Summary of Findings |
|---|---|
| Universal Screening with Autism Specific Tools | • No consensus for universal screening for an autism-specific tool (e.g., American Academy of Pediatrics vs. American Academy of Neurology and Child Neurology Society)<br>• Reasons cited in the research that both support and deny the need for universal screening<br>• Very few studies have examined the full continuum from screening ->referral ->treatment |
| Autism-Specific Screening Tools | • No gold standard autism-specific screening tool<br>• Generally tools that combine parent survey report along with provider observation of short parent follow up interview are more effective<br>• Promising tools for primary care: M-CHAT, Autism Screening Questionnaire<br>• Autism Behavior Checklist (ABC) and ATEC are measures for tracking changes/monitoring outcomes |
| Integrating Screening into Practice | • 1/3 or fewer providers use standardized Developmental Disorder screeners, even fewer Autism Spectrum Disorder screeners<br>• Implementation of screening is generally well-received by PC providers and can be consistently administered<br>• Need to train providers, not just implement tool |
| Electronic Health Record and ASD Practices | • Strong evidence that the implementation of EHR-based measures for developmental screening is feasible<br>• Biggest challenges is the inability to identify screenings and abnormal findings consistently across eligible patient encounters<br>• Common developmental screening instrumental might encourage greater consistency |

## 3.2 Measure Recommendations

Table 4 provides an overview of current Autism related measures included in the MU program. Table 5 includes an overview of the ONC-SAMHSA BH TEP's recommendations related to developing a BH CQM for the Autism domain.

Table 4. Behavioral Health Domain: Autism - *CURRENT POLICY*

| Source | Result |
|---|---|
| Meaningful Use Stage 1—Final Rule | No measures identified for this clinical domain |
| Meaningful Use Stage 2— Final Rule | No measures identified for this clinical domain |

Table 5. Behavioral Health Domain: Autism - *FUTURE RECOMMENDATIONS*

| Source | Recommendations |
|---|---|
| NQF Endorsed Measures – future consideration | Two measures related to this clinical domain<br>• NQF 1399: Developmental screening by 2 years of age. Steward: National Committee for Quality Assurance (NCQA)<br>• NQF 1385: Developmental screening using a parent-completed screening tool—Parent report, Children 0–5.<br>• Steward: Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Oregon Health and Science University (OHSU). |
| Clinical Evidence | Recommendations for additional research focused on:<br>• Standardized screening and assessment tools appropriate for primary care<br>• Integrating screening into real world practice<br>• Biomarkers for Autism |

In addition to the research summarized in the table above, several TEP discussions should be highlighted:

**MEASURE GAP—No Stage 1 or Stage 2 CQMs:** The Autism domain is in its infancy in terms of overall CQM development and the MU program. There are currently no measures developed and/or included in Stage 1 or Stage 2 of MU. The outcome goals of the TEP discussions for this domain were to:

- Identify the state of evidence to support an Autism screening in the primary care setting and the state of available CQMs related to Autism
- Determine whether there is clear research and data to support the development of a CQM for Autism
- Determine the priority of the next steps for measure development in this domain

**NEW MEASURES—Research:** There was general consensus among TEP members that NQF measure 1399, Developmental screening by 2 years of age, is currently the most promising NQF-endorsed measure to leverage for future development of an Autism-specific screening for the MU program. Additionally, since research indicates that Autism presents differently across age, intellectual ability, and spectrum type, a suite of measures is suggested for diagnostic accuracy. This suite may include an enhanced NQF 1399 measure along with others. Further research is

warranted prior to recommending specific enhancements of NQF 1399 and development of a measure or suite of measures to screen for Autism.

# 4 Future Recommendations

Though the focus of this project is to recommend CQMs for the HITECH MU program, the TEP was also asked to make recommendations for additional research and development needed to support the next phases of measure development for this domain. These recommendations include:

- **Universal Screening Methods**

  The American Academy of Pediatrics (AAP) and other organizations endorse the deployment of a universal screening for Autism. However, there is not currently sufficient evidence to support population based screening. The TEP highlighted the need for additional research to support the adoption of a standardized diagnostic tool for Autism screening was noted by the TEP. Many screens have been tested but there is not enough evidence to support the use of any one screen.

- **Integrating Screening into Practice**

  According to the literature on provider behaviors and attitudes, screening and referral practices are currently inconsistent within primary care settings. Development of best practices for clinical management in real world settings has promise for improving the delivery of quality care, and should include:

  – Comprehensive training on assessment/diagnostic issues for first-line screeners

  – Appropriate referrals and access to qualified professionals

  Much of the current research focuses on conducting screenings within primary care and referring patients with a positive screen to a highly specialized research center. As most patients across the country will not have access to this level of expertise we need more research focused on implementation strategies within healthcare settings that are accessible in most communities and that are manageable in an already overburdened healthcare system.

- **Misdiagnosis and Reducing Health Disparities**

  Research indicates that there are racial and ethnic disparities in the identification and diagnosis of both children and adults with Autism. In part, this may be due to the absence or lack of diagnostic training specific to Autism for BH professionals, especially for older cohorts. Efforts to increase awareness of Autism diagnostic criteria and to develop standard screening and assessment tools that are valid across diverse populations are needed to minimize misdiagnoses and potentially reclassify existing misdiagnosed cases.

- **Biomarkers**

  TEP members also highlighted the need for further investigation of the feasibility of using biomarkers to screen for autism and suggested that microarray analysis or other biological testing could eventually serve as the foundation for CQMs for identification of patients with Autism.

- **Future Measure Development**

  The TEP recommendations for a long-range vision for an Autism CQM set included:

- Conducting an initial general screening that detects developmental delays and/or disorders (NQF 1399)
- Retooling NQF 1385, currently a parent completed survey based measure, to an EHR based measure
- Completing a composite measure that records screening results and referrals
- Completing a comprehensive diagnostic screening using Autism-specific measures (e.g., interview-based screenings, biomarkers)

# 5 Conclusion

The ONC-SAMHSA Behavioral Health CQM TEP, Autism domain subgroup, determined that while the Autism domain currently lacks CQMs suitable for the program opportunities exist to advance quality reporting for this domain with the development of new measures based on emerging clinical research. More research is needed to support the development of a set of measures that will specifically support identification of and initiation of treatment for patients with Autism.

# Appendix A TEP Member List

**COMMUNITY MEMBERS**

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# Appendix B Meeting Schedule

| BH CQM TEP Schedule and Topics – Revised 7/6/12 | | |
|---|---|---|
| **Week #** | **Week Of** | **Topic** |
| 1 | 4/9-4/13 | KICK-OFF –<br>OPTION 1: 4/9: 1:00P-3:00P<br>OPTION 2: 4/12: 12:30P–2:30P |
| 2 | 4/16 3-4:30pm Eastern | Suicide/Trauma – Week 1 |
| 3 | 4/23 3-4:30pm Eastern | Autism – Week 1 |
| 4 | 4/30 3-4:30pm Eastern | Depression – Week 1 |
| 5 | 5/7 3-4:30pm Eastern | Drugs/Alcohol – Week 1 |
| 6 | 5/14 3-4:30pm Eastern | Suicide/Trauma – Week 2 |
| 7 | 5/21 3-4:30pm Eastern | Autism – Week 2 |
| 8 | **5/29 3-4:30pm Eastern** | Depression – Week 2 |
| 9 | 6/4 3-4:30pm Eastern | Drugs/Alcohol – Week 2 |
| 10 | 6/11 3-4:30pm Eastern | Suicide/Trauma – Week 3 |
| 11 | **6/22 3-4:30pm Eastern** | Autism – Week 3 |
| 12 | 6/25 3-4:30pm Eastern | Depression – Week 3 |
| 13 | **7/2 3-4:30pm Eastern** | **CANCELLED** |
| 14 | 7/9 3-4:30pm Eastern | Drugs/Alcohol – Week 3 |
| | | |
| **TEP PHASE II** | | |
| 15 | 7/16 3-4:30pm Eastern | Depression – Week 1 |
| 16 | 7/23 3-4:30pm Eastern | Drug Use/PDM – Week 1 |
| 17 | 7/30 3-4:30pm Eastern | Depression – Week 2 * |
| 18 | 8/6 3-4:30pm Eastern | Drug Use/PDM – Week 2 * |
| ADDED | **8/9 All day event** | **In person and Webinar** |
| 19 | 8/13 3-4:30pm Eastern | Depression – Week 3 * |
| 20 | 8/20 3-4:30pm Eastern | Drug Use/PDM – Week 3 * |
| 21 | 8/27 3-4:30pm Eastern | Depression – Week 4 * |
| 22 | 9/3 3-4:30pm Eastern | Drug Use/PDM – Week 4 * |
| 23 | 9/10 3-4:30pm Eastern | Depression – Week 5 * |
| 24 | 9/17 3-4:30pm Eastern | Drug Use/PDM – Week 5 * |
| | | *if needed |

# Appendix C Environmental Scans

## C.1 NQF-Endorsed Measures

## C.2 AHRQ Measures (Non-NQF-Endorsed)

## C.3 Clinical Literature Search Matrix

## C.4 Clinical Literature Search Summary

# High Priority AUTISM Clinical Quality Measures for Meaningful Use (Federal Subgroup – 12/15/11)

| NQF # | Measure Title | Measure Description | Numerator Statement | Denominator Statement | Measure Steward | Link to NQF website |
|---|---|---|---|---|---|---|
| 1399 | Developmental Screening by 2 Years of Age | The percentage of children who turned 2 years old during the measurement year who had a developmental screening performed between 12 and 24 months of age. | Children who had documentation in the medical record of a developmental screening (screening for risk of developmental, behavioral and social delays) between 12 and 24 months of age. Screening must be conducted using a standardized tool. | Children with a visit who turned 2 years of age between January 1 and December 31 of the measurement year. | NCQA | http://www.qualityforum.org/MeasureDetails.aspx?actid=0&SubmissionId=1399#k=1399&e=1&st=&sd=&s=n&so=a&p=1&mt=&cs=&ss= |
| 1385 | Developmental screening using a parent completed screening tool (Parent report, Children 0-5) | The measure assesses whether the parent or caregiver completed a developmental screening tool meant to identify children at-risk for developmental, behavioral and social delays. The items are age-specific and anchored to parent-completed tools (a majority of health care providers implementing the Bright Futures recommendations for | Percentage of children whose parents completed a standardized developmental screening tool to identify children at risk for developmental, behavioral, and social delays at a health care visit during the previous | Children age 10 months - 5 years (71 months) with a health care visit in the past 12 months (see 2a.8 below for further definition of "health care visit") | Maternal and Child Health Bureau, Health Resources & Services Administration | http://www.qualityforum.org/MeasureDetails.aspx?actid=0&SubmissionId=1385#k=1385&e=1&st=&sd=&mt=&cs=&ss=&s=n&so=a&p=1 |

| NQF # | Measure Title | Measure Description | Numerator Statement | Denominator Statement | Measure Steward | Link to NQF website |
|---|---|---|---|---|---|---|
| | | standardized screening for all children utilize parent-completed tools due to their validity and feasibility). The age-specific items assess whether children 10-71 months are screened. | 12 months | | | |
| | | | | | | |
| | | | | | | |

# Domain: Autism (Keyword: Autism) – Environmental Scan

## Search Criteria: Autism and Ambulatory

- **29 results initially identified**
  - 2 removed (NQF endorsed)
- **Final pool = 27 results for review**

## Full List of Original Results*

**(*includes NQF endorsed measures)**

**Click Here**

# Domain: Autism (Keyword: Autism) – Top Results

| | Measure Review (M= maybe, X=No, Y = yes) | Prioritized Result Summary |
|---|---|---|
| 1 | ☐ | Learning disabilities: the practice can produce a register or patients aged 18 and over with learning disabilities. 2009 Mar. **[NQMC Update Pending]** NQMC:005120<br>British Medical Association - Medical Specialty Society; National Health Service (NHS) Confederation - National Government Agency [Non-U.S.]. |
| 2 | ☐ | Children with special health care needs: percentage of children who meet criteria for having special health care needs according to the Children with Special Health Care Needs Screener (CSHCN Screener). 2000 Oct. NQMC:006162<br>Child and Adolescent Health Measurement Initiative - Nonprofit Organization. |
| 3 | ☐ | Medical home: percentage of children and adolescents who meet the threshold for having a medical home according to a subset of questions from the 2007 National Survey of Children's Health. 2007 Apr. NQMC:005619<br>Child and Adolescent Health Measurement Initiative - Nonprofit Organization; Maternal and Child Health Bureau of the Health Resources and Service Administration - Federal Government Agency [U.S.]; National Center for Health Statistics of the Centers for Disease Control and Prevention - Federal Government Agency [U.S.]. |

# Domain: Autism (Keyword: Screening for Development) – Environmental Scan

**Search Criteria: Screening for Development, Ambulatory, Ages: Infant – 18 yo**

- **48 results initially identified**
  - 10 removed (NQF endorsed)
- **Final pool = 38 results for review**

**Full List of Original Results***
**(*includes NQF endorsed measures)**

**Click Here**

# Domain: Autism (Keyword: Screening for Development) – Top Results

| | Measure Review (M= maybe, X=No, Y = yes) | Prioritized Result Summary |
|---|---|---|
| 1 | ☐ | Children with special health care needs: percentage of children who meet criteria for having special health care needs according to the Children with Special Health Care Needs Screener (CSHCN Screener). 2000 Oct. NQMC:006162<br>Child and Adolescent Health Measurement Initiative - Nonprofit Organization. |
| 2 | ☐ | Routine prenatal care: percentage of all identified preterm birth (PTB) modifiable risk factors assessed that receive an intervention. 2010 Jul. NQMC:006320<br>Institute for Clinical Systems Improvement - Nonprofit Organization. |

| # | Citation | Year | Type: Topic | Population/ Subpopulations | | Study Setting | Screening Tools/ Measures | Summary Notes | Results/Findings | Weighted Relevance | | | TEP Review |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| **Universal vs. Selective** | | | | | | | | | | | | | |
| 1 | Allely, C. S. and P. Wilson (2011). "Diagnosing autism spectrum disorders in primary care." Practitioner 255(1745): 27-30, 23 | 2011 | Report: Screening | | | p.c. | | WHAT are the diagnostic criteria for ASD? HOW should children be assessed? WHICH patients should be referred? Lists risk factors for ASD and assessment tools | The evidence for developmental benefits of early intervention in ASD is largely based on observational studies. Overall, evidence supporting the use of autism-specific diagnostic tools, either individually or in combination, is poor, so the clinical benefits of using these tools remain uncertain. The NICE guidelines nevertheless acknowledged that both an autism-specific semistructured interview and observation are effective in implementing a structured means of collating information to aid diagnostic assessment. M-CHAT can be used for assessment of young children in primary care by GPs or health visitors when ASD is suspected. They can identify clinical features indicative of increased risk but should not be used to rule out ASD. M-CHAT is a promising instrument for the early detection of ASD. It fails to recognize 15% of children with the condition. | H3 | | | |
| 2 | Pandey, J., A. Verbalis, et al. (2008). "Screening for autism in older and younger toddlers with the Modified Checklist for Autism in Toddlers." Autism 12(5): 513-535. | 2008 | Single Study: Screening | younger (16- 23 mo.) older (24-30 mo.) | low risk; high risk | larger sample of families in fed. funded study | Modified Checklist for Autism in Toddlers (M-CHAT) | 4 groups- younger/low risk; older/low risk; younger/high risk; older/high risk | parents of younger/low risk children more likely to refuse evaluation than parents of high risk children; most of children in all groups were diagnosed with a developmental disorder-symptom severity did not differ among groups; | | M2 | | |
| 3 | Lipkin & Hyman (2011). Should All Children Be screened for Autism Spectrum Disorders | | | | | | | counterpoint article to [Campos-Outcalt, D. (2011). "Should all children be screened for autism spectrum disorders? No: screening is not ready for prime time." Am Fam Physician 84(4): 377-378.] | studies indicateASD screening improves with repeated sur¬veillance using screening tests and struc¬tured observations. Although false-positive screening may result in stress, anxiety, and expense of diagnostic evaluation, other developmental disorders are often diagnosed in children who falsely test posi¬tive for an ASD. False-positive rates can be decreased with follow-up interview visit. parents consistently report dissatisfaction with the care provided by their physicians, including lack of expertise using screening tools and delay in acting on their concerns. Screening offers the potential for early treatment, which can lessen the effect of a condition. This is true for ASDs and related disorders in which randomized con¬trolled trials have demonstrated improve¬ments in young children with ASDs with regard to parent-child social communica¬tion, socially engaged imitation, joint attention, and core behavioral symptoms of autism. systematic review of early intensive interventions also found improvements in cognitive performance, language skills, and adaptive behavioral skills in young children with ASDs using behavioral interventions or more compre¬hensive approaches using developmental and behavioral frameworks | H3 | | | |

| # | Citation | Year | Type: Topic | Population/ Subpopulations | | Study Setting | Screening Tools/ Measures | Summary Notes | Results/Findings | Weighted Relevance | | | TEP Review |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 4 | Barton, M. L., T. Dumont-Mathieu, et al. (2011). "Screening Young Children for Autism Spectrum Disorders in Primary Practice." J Autism Dev Disord. | 2011 | Review: Screening | <24 mos. | | p.c. | | Reviews early screening tools currently in use and offers recommendations for integrating autism specific screening into primary care | despite a limited data base regarding the psychometric properties of specific screeners, the value of screening far exceeds the risks;there is insufficient data to support using broadband developmental screeners in lieu of autism specific screeners. there is clear and disconcerting evidence of disparities in the early identification of children with ASDs based on racial and ethnic group membership and socioeconomic status; There are well-studied instruments which can provide quick and accurate screening in the context of ongoing developmental surveillance and thoughtful elicitation/ clarification of parental concerns. | H1 | | | |
| 5 | Pierce, K., C. Carter, et al. (2011). "Detecting, studying, and treating autism early: the one-year well-baby check-up approach." J Pediatr 159(3): 458-465 e451-456. | 2011 | Single Study: Sceening | 12-24 mo. | | p.c. | | The Communication and Symbolic Behavior Scales Developmental Profile Infant-Toddler Checklist was distributed at every 1-year pediatric check-up; 137 pediatricians and 225 infants participated. Screens were scored immediately, and failures referred for further evaluation | Pediatricians screened 10 479 infants at the 1-year check-up; 184 infants who failed the screen were eval- uated and tracked. To date, 32 infants received a provisional or final diagnosis of ASD, 56 of LD, nine of DD, and 36 of ‘‘other.’’ Five infants who initially tested positive for ASD no longer met criteria at follow-up. The remainder of the sample was false positive results. Positive predictive value was estimated to be .75. | | M2 | | |
| 6 | Zwaigenbaum, L. (2010). "Advances in the early detection of autism." Curr Opin Neurol 23(2): 97-102. | 2010 | Review: Screening | toddlers | | | | discusses previous and prospective studies for screening | Recent advances in early detection research have resulted from prospective studies of high-risk infants and large ASD screening studies conducted in community settings; exciting progress has been made in establishing the efficacy of ASD-specific interventions; increasing emphasis on opportunities to link early behavioral expression to the underlying neurobiology of ASD, potentially bringing us closer to the fundamental mechanisms underlying this disorder. | | M1 | | |
| 7 | Oosterling, I. J., M. Wensing, et al. (2010). "Advancing early detection of autism spectrum disorder by applying an integrated two-stage screening approach." J Child Psychol Psychiatry 51(3): 250-258. | 2010 | Single Study: Screening | 0-11 years | experimental region-referred for clinical psychiatric evaluation | p.c. | diagnostic protocol-psychiatric evaluation, administration of the ADOS and/or the ADI-R, assessment of cognitive and language skills; IQ- age appropriate psychometric | develop and evaluate a clinically relevant integrated early detection programme based on two stage screening approach/ 1)train relevant professionals to recognize early signs of autism and use ESAT 2)use specific referal protocal 3) build multidisciplinary diagnostic team | ASD dx'ed 21 mo earlier for children in experimental region w/ mean age of dx decreasing by 19.5 mo. From baseline in the experimental region; children in experiemental region were 9.4x more likely to be diagnosed before age 36 mo. ; in combination, training health professionals in the early signs of autism & using the ESAT screen & a clear referral and diagnostic pathway reduced age of dx from 83 to 64 months. proportion of cases dx'ed before 24 months increased from 12.7% to 24.3%. | H2 | | | |
| 8 | Inglese, M. D. (2009). "Caring for children with autism spectrum disorder. Part II: screening, diagnosis, and management." J Pediatr Nurs 24(1): 49-59. | 2009 | Review: Screening | infants + toddlers < 3 years | | p.c. | | reviews screening and diagnosis; infants and toddlers development, and ASD; treatment and ongoing management | Autism Behavior Checklist (ABC) has not been particularly helpful in screening or diagnosis, but it is helpful in tracking changes in a child already having an autism spectrum diagnosis. The ABC is thus also useful when monitoring treatment responses | | M1 | | |

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| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 9 | Zwaigenbaum, L., S. Bryson, et al. (2009). "Clinical assessment and management of toddlers with suspected autism spectrum disorder: insights from studies of high-risk infants." Pediatrics 123(5): 1383-1391. | 2009 | Review: Screening | < 2 years | high risk infants | p.c. | | review of findings from recent studies on early development of children with ASD, summarizing current knowledge on early signs of ASD, screening properties of early detection tools, current best practice for ASD before 2 years of age | ASD-specific screeners can potentially identify toddlers with ASD who are not flagged by either parents or clinicians in a general surveillance context. Need to reduce the time between initial emergence of ASD symptoms and referral for specialized assessments. For those under 2, need to assess social & communication development using both direct observation & parent report. Under 2 years old, often difficult to differentiate ASD sxs from other types of DD. Mild/absence of sxs at 18 mos. do not r/o ASD so on-going surveillance & follow-up are essential. Few studies of stability of ASD dx when dx before age 2. Dx after age 2 tends to be stable. Positive screener/concerns should be followed by audiologic testing. | H1 | | | |
| 10 | Nadel, S. and J. E. Poss (2007). "Early detection of autism spectrum disorders: screening between 12 and 24 months of age." J Am Acad Nurse Pract 19(8): 408-417. | 2007 | Review: Screening | 12-24 mo. | | p.c. | | present NPs with info on screening for ASDs in children between 12-24 mo.; rec. provided for appropriate referrals and initiation of early intervention | Children with ASD exhibit impaired social interaction, verbal and nonverbal communication deficits, and repetitive, restricted, and stereotyped patterns of behavior or interests. Studies show that these children benefit from beginning intensive EI as soon as possible. | | M1 | | |
| 11 | Robins, D. L. and T. M. Dumont-Mathieu (2006). "Early screening for autism spectrum disorders: update on the modified checklist for autism in toddlers and other measures." J Dev Behav Pediatr 27(2 Suppl): S111-119. | 2006 | Review: Screening | toddlers | | p.c. | | | there are limited data on whether general screening instruments such as the PEDS and the ASQ have high sensitivity specifically for the identification of children at risk for an ASD. evaluating the ASD-specific psychometric properties of broad screening tools such as the PEDS and the ASQ is critical. Future research is required to further investigate this issue. To date, the M-CHAT appears to be a promising tool for the early detection of ASD. Because cross-validation is currently underway, practitioners are cautioned when using the M-CHAT to screen clinical samples, particularly without the structured follow-up interview. | H1 | | | |
| 12 | Posserud, B., A. J. Lundervold, et al. (2008). "Factor analysis of the Autism Spectrum Screening Questionnaire." Autism 12(1): 99-112. | 2008 | Single Study: Screening | 7-9 yr old | general | home/school | Autism Spectrum Screening Questionnaire (ASSQ); Strengths and Difficulties Questionnaire | investigates factor structure of parent and teacher ASSQ- for validation correlated with results of SDQ | most variance was explained by one factor incl. measures of social function, validated with high correlation with SDQ peer problems scale; second factor incl. measures of autism assoc. problems.; third factor were more spec. to cognitive style typically found in high functioning autism/Asperger syndrome | | | L3 | |
| 13 | Noland, R. M. and R. L. Gabriels (2004). "Screening and identifying children with autism spectrum disorders in the public school system: the development of a model process." J Autism Dev Disord 34(3): 265-277. | 2004 | Review: Screening | children | | school | | purpose: develop a basic level of training and competence in recognizing and serving students who have an ASD by (1) providing an overview of the legal and clinical issues involved in screening for children with ASD within the school system, (2) defining a school-based professional training process and (3) outlining a school-based ASD screening process. | model of screening and assessment service delivery by a multidisciplinary team described in this summary article has been working very well | | | L3 | |

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| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 14 | Nelson, H. D., P. Nygren, et al. (2006). "Screening for speech and language delay in preschool children: systematic evidence review for the US Preventive Services Task Force." Pediatrics 117(2): e298-319. | 2006 | Review: Screening | preschool | | p.c. | | evaluate strengths and limits of evidence about effectiveness of screenings and interventions for speech and language delay in pre-school aged children to determine balance of benefits and adverse effects of routine screening in primary care | Although brief evaluations are available and have been used in a number of settings with administration by professional and nonprofessional individuals, including parents, the optimal method of screening for speech and language delay has not been established | | M1 | | |
| 15 | Mousmanis, P. and W. J. Watson (2008). "The 18-month well-child visit in primary care: Clinical strategies for early intervention." Paediatr Child Health 13(10): 845-849. | 2008 | Review: Screening | 18 mo. | | p.c. | | reports on evidence based interventions at the 18 mo. visit including screening tools, resources, and a case example; importance of interdisciplinary coordination to provide a comprehensive approach to screening, assessment, and intervention for developmental delays in infants and young children | | H1 | | | |
| 16 | Allison, C., B. Auyeung, et al. (2012). "Toward brief "red flags" for autism screening: the short autism spectrum quotient and the short quantitative checklist in 1,000 cases and 3,000 controls." J Am Acad Child Adolesc Psychiatry **51**(2): 202-212 e207. | 2012 | Single Study: Screening | toddler, children, adolescents, adults | indv. with ASD | p.c. | Autism Spectrum Quotient (AQ); Quantitative Chacklist for Autism in Toddlers (Q-CHAT) | ID 10 items on AQ and Q-CHAT with good test accuracy | At a cut-point of 6: AQ-10 adult, sens-0.88, spec-0.91, PPV- 0.85; AQ-10 adolescent, sens-0.93, spec-0.95, PPV-0.86; AQ-10 child, sens- 0.95, spec- 0.97, PPV-0.94. At a cut-point of 3 on the Q-CHAT-10, sens-0.91, spec-0.89, PPV- 0.58. Internal consistency was 0.85 on all measures; short measures have potential to aid referral decision making for specialist assessment and should be further evaluated. | H2 | | | |
| 17 | Miller, J. S. (2011). "The Each Child Study: Systematic Screening for Autism Spectrum Disorders in a Pediatric Setting." Pediatrics. | 2011 | Single Study: Screening | 14-30 mo. | general | p.c. | M-CHAT; ITC | investigate feasibility and outcome of systematic autism screening process for all toddlers in large community based pediatric practice; | of those screened- 3 already been diagnosed with ASD,, 10 showed signs of early ASD; formal screening measures identified more children with ASD than clinical judgement/caregiver concern | H2 | | | |
| 18 | Lubetsky, M. J. (2008). "Recognition of Autism Spectrum Disorder." Speaker's Journal 8(4). | 2008 | Review: Screening | toddler, children, adolescents, adults | | p.c. | | diagnostic criteria and clinical characteristics for autism; discussion of programs supporting the early recognition of autism, description of key signs and symptoms that would warrant referral for screening; specifics of autism assessment-key issues/considerations; three stage approach to autism diagnostic assessment | early ID requires statewide training in warning signs/symptoms of autism for indv. who work with young children; early diagnosis requires training of professionals; assessment req. multidisciplinary team approach; availability of specialized early intervention services needs to be enhanced; diagnostic and reatement services needs to be available for older children, adolesc, and adults | H1 | | | |
| 19 | Autism Spectrum Disorders: State Part C and Part B Initiatives to Serve a Growing Population | 2009 | Review: Screening | | | | | using customized protocols, Project Forum conducted nine interviews with 11 SEA and Part C lead agency staff from CA, MA, MI, MO, OK; describes approaches these states are using as part of their initiatives to ID and address the needs of children and youth with ASD | state agencies use a variety of approaches to address the early intervention and special ed needs; most common approaches are improving training of inservice professionals who search children with ASD, and TA efforts through state resource centers, direct consultation, and the development and dissemination of best practice guidelines | | M3 | | |
| 20 | AAN Guideline Summary for Clinicians- Screening and Diagnosis of Autism | | Review: Screening | | | p.c. | | guideline on screening and diagnosis of autism; reviews available empirical evidence and gives specific recommendations for ID; | requires dual process 1)routine developmental surveillance and screening performed on all children to ID those at risk for any atypical development 2)diagnose and evaluate autism to differentiate autism from other dev. disorders | | M3 | | |

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|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 21 | Johnson, C. P., S. M. Myers, et al. (2007). "Identification and evaluation of children with autism spectrum disorders." Pediatrics 120(5): 1183-1215. | 2007 | Review: Screening | | | p.c. | | includes definition, history, epidemiology, diagnostic criteria, early signs, neuropathologic aspects, etiologic possibilities; provides algorithms to help pediatrician develop strategy for early ID | | H1 | | | |
| 22 | Compare Screening Tools-Validity Properties Chart <http://www.developmentalscreening.org/screening_tools> | | Guideline: Screening | | | p.c. | | | | H1 | | | |
| 23 | Biederman, J., C. R. Petty, et al. (2010). "Child behavior checklist clinical scales discriminate referred youth with autism spectrum disorder: a preliminary study." J Dev Behav Pediatr **31**(6): 485-490. | 2010 | Single Study: Screening | ASD- 11.2; non-ASD-12.1 | ASD vs. non ASD | p.c. | Child Behavior Checklist | stepwise logistic regression used to ID those scales that best predicted ASDs when compared with non-ASD comparison group | best independent predictors: Withdrawn, Social Problems, and Thought Problems | | M2 | | |
| **Universal vs. Selective: Studies/Reviews not supporting universal ASD screen** | | | | | | | | | | | | | |
| 24 | Al-Qabandi, M., J. W. Gorter, et al. (2011). "Early autism detection: are we ready for routine screening?" Pediatrics 128(1): e211-217 | 2011 | Review: Screening | | | p.c. | | | no autism screening programs have been studied in randomized controlled trials; early internsive behav. intervention, at best, produced modest results in selected subgroups; sensitivity/specificity of screening tools vary depending on age and symptom severity; M-CHAT promising but unable to recognize 15 of 100 children with autism; no strong evidence of effectiveness of therapies and availability limited (wait lists) and cost is prohibitive; on basis of available research-- not enough sound evidence to support implementation of routine population based screening for autism | H3 | | | |
| 25 | Williams, J. and C. Brayne (2006). "Screening for autism spectrum disorders: what is the evidence?" Autism 10(1): 11-35. | 2006 | Review: Screening | preschool/ primary school aged | | | | examines evidence for screening for ASD in general population and information needed to inform screening policy; comprehensive review of individual screening measures | no screening test suitable for use in a population setting that has been fully validated; insufficient evidence regarding the effectiveness of interventions; on basis of existing evidence, screening for ASD cannot be recommended | H1 | | | |

| # | Citation | Year | Type: Topic | Population/ Subpopulations | | Study Setting | Screening Tools/ Measures | Summary Notes | Results/Findings | Weighted Relevance | | | TEP Review |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 26 | Campos-Outcalt, D. (2011). "Should all children be screened for autism spectrum disorders? No: screening is not ready for prime time." Am Fam Physician 84(4): 377-378. | 2011 | Review: Screening | children | | p.c. | | counterpoint article to [Lipkin & Hyman (2011)] | Council on Children with Disabilities report on ASDs reveals that none of the following questions are answered: • What are the se & PPV of the best screening test for ASDs available in an average clinical setting? • How much earlier can screening tests detect ASDs compared with an astute clinician who asks a few key questions about, and acts on, parental concerns regard¬ing a child's communication and interactions? • What are the potential harms of testing? (Potential harms are not even considered in the report.) • Does earlier detection by screening result in mean¬ingful and long-lasting improvements compared with detection through routine care? The Council on Children with Disabilities report lists only five references to support the belief that early interven¬tion is beneficial- none of these references provide any convincing evidence to support this claim. Several reviews of this question, using different methods, have come up with different conclusions. Several guideline panels in other countries have conducted a review using robust assessment meth¬ods and recommended against universal screen¬ing; do not really know if interventions help those younger than age 2. The most recent systematic review of early interventions in US concluded that strength of evidence for interventions for children younger than two is "insufficient." | H3 | | | |
| 27 | Oosterling, I. J., S. H. Swinkels, et al. (2009). "Comparative analysis of three screening instruments for autism spectrum disorder in toddlers at high risk." J Autism Dev Disord **39**(6): 897-909. | 2009 | Single Study: Sceening | mean 29.6 mo. | at risk | p.c. | Early Screening of Autistic Traits Questionnaire; Social Communication Questionnaire;, Communication and Symbolic Behavior Scales-Developmental Profile; Infant-Toddler Checklist; key items of the Checklist for Autism in Toddlers | discriminative properties are compared in the whole sample and in two age groups seperately (8-24mo. And 25-44 mo.) | Strictly speaking, not one single screening instrument investigated appears to meet standards for a satisfactory prediction of an ASD diagnosis in our high-risk sample of very young children, as no instrument demonstrates acceptable diagnostic accuracy for all four indices (Se, Sp, PPV, NPV), Balance between the sensitivity and specificity of the screens, as expressed by the AUCs, is fair at the most. None of the instruments performs clearly better than another in differentiating between ASD and non-ASD. However, it would be too simple and premature to dismiss all these instruments altogether, as each instrument shows specific strengths that should be considered in making decisions about which instrument to use for which purpose. | | M2 | | |
| 28 | Allaby, M., Sharma, M. (2011). "Screening for Autism Spectrum Disorders in Children below the age of 5 years: A draft report for the UK National Screening Committee" | 2011 | Report: Screening | below age 5 | ASD | p.c. | | reviews screening for ASD in children below age of 5 years against UK Nat'l Screening Committee criteria for appraising the viability, effectiveness and appropriateness of a screening programme | gaps in the evidence regarding the test and treatment suggest that implementation of a screening programme would be premature | H1 | | | |
| **Screening Measures- Psychometric Properties** | | | | | | | | | | | | | |
| 29 | Allison, C., J. Williams, et al. (2007). "The Childhood Asperger Syndrome Test (CAST): test-retest reliability in a high scoring sample." Autism **11**(2): 173-185. | 2007 | Single Study: Sceening | unselected toddlers-21mo.; ASC-44mo. | unselected toddlers; Autism Spectrum Condition | p.c. | Childhood Asperger Syndrome Test (CAST) | test-re test reliability of CAST- 73 parents filled in second CAST within approx 2 mo. of first CAST administration; Agreement of above and below cut point of 15 investigated | kappa statistic of for agreement was .41; 70% of children did not move across cut-point of 15; correlation between two test scores=.67; mmoderate test-retest reliability in high scoring sample | | | L2 | |

| # | Citation | Year | Type: Topic | Population/ Subpopulations | | Study Setting | Screening Tools/ Measures | Summary Notes | Results/Findings | Weighted Relevance | | | TEP Review |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 30 | Dereu, M., R. Raymaekers, et al. (2012). "Can child care workers contribute to the early detection of autism spectrum disorders? A comparison between screening instruments with child care workers versus parents as informants." J Autism Dev Disord **42**(5): 781-796. | 2012 | Single Study: Sceening | 5.57 mo.-48.13 mo. | at risk | home/p.c. | Checklist for Early Signs of Developmental Disorders (CESDD) | inter-rater validity- between child care workers and parents; sample of 357 children between 5.57 and 48.13 mo. Who show sign ofs of ASD or language delay | discriminant power of CESDD was as good as that of parent questionnaire | | | L2 | |
| 31 | Dereu, M., H. Roeyers, et al. (2012). "How useful are screening instruments for toddlers to predict outcome at age 4? General development, language skills, and symptom severity in children with a false positive screen for autism spectrum disorder." Eur Child Adolesc Psychiatry. | 2012 | Single Study: Sceening | 2 yrs/ 4 yrs | at risk | p.c. | Checklist for Early Signs of Developmental Disorders (CESDD); Early Screening of Autistic Traits (ESAT) | looking at predictive validity of positive screens on CESDD and ESAT at age 2 towards language, cognitive function, and symptom severity at age 4 | children who screened positive on ESAT scored lowed for both language and cognitive functioning at age 4; the more signs of ASD that were recognized on CESDD/ESAT, lower the score for language and cogn. functioning at age 4; false positive screens could be differentiated from true positive screens on the CESDD only in symptom severity score on the ADOS; early screeners for ASD also detect children with other developmental disorders | | M2 | | |
| 32 | DeVincent, C., K. D. Gadow, et al. (2008). "Screening for autism spectrum disorder with the Early Childhood Inventory-4." J Dev Behav Pediatr **29**(1): 1-10. | 2008 | Single Study: Sceening | 3-5 years old | ASD; non ASD psychiatric | p.c. | Early Childhood Inventory-4 | clinical utility of ASD scoring algorithms for ECI-4 | ECI-4 shows promise as a clinically useful screening measure for ASD in clinic-referred and preschool children | | M2 | | |
| 33 | Eaves, L. C., H. D. Wingert, et al. (2006). "Screening for autism spectrum disorders with the social communication questionnaire." J Dev Behav Pediatr 27(2 Suppl): S95-S103. | 2006 | Single Study: Screening | 2-3 year old; 4-6 year old | general | p.c. | Modified Checkist for Autism in Toddlers (M-CHAT); Social Communication Questionnaire (SCQ) | MCHAT given to parents of 2-3 yr old/SCQ given to parents of 4-6 yr old | both measures sensitivity was higher than specificity; results bettter for parents who spoke English as a second language | | M2 | | |
| 34 | Frazier, T. W., E. A. Youngstrom, et al. (2012). "Validation of proposed DSM-5 criteria for autism spectrum disorder." J Am Acad Child Adolesc Psychiatry **51**(1): 28-40 e23. | 2012 | Single Study: Sceening | 2-18 yr old | ASD; non-ASD | p.c. | Social Responsiveness Scale; Social Communication Questionnaire (SCQ) | evaluate the validity of proposed DSM 5 criteria for ASD | DSM 5 criteria had supeior specificity elative to DSM IV-TR criteria but lower sensitivity; relaxing DSM V criteria by requiring one less symptom criterion increased sensitivity with minimal reduction in specificity | | | L2 | |
| 35 | Ghuman, J. K., S. L. Leone, et al. (2011). "The screen for social interaction (SSI): a screening measure for autism spectrum disorders in preschoolers." Res Dev Disabil **32**(6): 2519-2529. | 2011 | Single Study: Sceening | younger-24-42 mo (mean 34.1 mo.); older-43-61 mo. (mean 52.4 mo.) | ASDs, non-ASD developmental and/or psychiatric dsorders, or without developmental concerns | p.c. | Ghuman-Folstein Screen for Social Interaction (SSI) | caregivers of 350 children with ASDs, non-ASD developmental and/or psychiatric dsorders, or without developmental concerns completed SSI | SSI-Y and SSI-O showed moderate convergence with Asd diagnostic measures and significantly differentiated ASD and non-ASD clinical groups; sensitivity and specificity for both around .85 and 70 respectively | | M2 | | |

| # | Citation | Year | Type: Topic | Population/ Subpopulations | | Study Setting | Screening Tools/ Measures | Summary Notes | Results/Findings | Weighted Relevance | | | TEP Review |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 36 | Goin-Kochel, R. P. and R. Cohen (2008). "Screening cases within a statewide autism registry: a comparison of parental reports using DSM-IV-TR criteria versus the SCQ." Focus on Autism and Other Developmental Disabilities **23**(3): 148-154 | 2008 | Single Study: Sceening | mean age-9.5 years | general | p.c. | generated from criteria outlined by DSM-IV-TR; Social Communication Questionnaire (SCQ) | parent/caregivers completed both measures and data used to determine the number of cases likely to have autism | DSM IV TR questionnaire-94.3% met criteria for probable autism; SCQ-88.6% met criteria; two instruments agreed on 89% of the cases | | M2 | | |
| 37 | Gray, K. M., B. J. Tonge, et al. (2008). "Screening for autism in young children with developmental delay: an evaluation of the developmental behaviour checklist: early screen." J Autism Dev Disord 38(6): 1003-1010. | 2008 | Single Study: Sceening | 20-51 mo. | general | p.c. | Developmental Checklist Early Screen (DBC-ES) | parents complete DBC-ES before child undergoes assessment | good interrater agreement and internal consistency; significant correlations with clinician completed measure of autism symptomatology; high sensitivity | H2 | | | |
| 38 | Hallerod, S. L., T. Larson, et al. (2010). "The Autism--Tics, AD/HD and other Comorbidities (A-TAC) telephone interview: convergence with the Child Behavior Checklist (CBCL)." Nord J Psychiatry **64**(3): 218-224. | 2010 | Single Study: Sceening | 9-12 years | general | p.c. | Inventory of Autism-Tics, Attention deficit/Hyperactivity Disorder (AD/HD) and other Comorbidities (A-TAC); Child Behavior Checklist | compare telephone interview screening using A-TAC with results from CBCL | A-TAC has convergent validity with CBCL in several problem areas but A-TAC also provides more detailed and specific assessments of ASD symptoms | | M2 | | |
| 39 | Honda, H., Y. Shimizu, et al. (2009). "Extraction and Refinement Strategy for detection of autism in 18-month-olds: a guarantee of higher sensitivity and specificity in the process of mass screening." J Child Psychol Psychiatry 50(8): 972-981. | 2009 | Single Study: Sceening | 18 mo. | at risk | p.c. | Young Autism and other developmental disorders checkup tool (YACHT-18 | E&R Strategy= extraction stage-all cases at risk of childhood problems identified; refinement stage- cases without problems excluded, leaving only cases w/ conclusive diagnoses | extraction stage produced 4 false negatives- sensitivity 60% for autistic and 82.6% for developmental; specificity for developmental disorders rose to 100% with E&R strategy | H2 | | | |
| 40 | Ingram, D. H., S. D. Mayes, et al. (2007). "Assessing children with autism, mental retardation, and typical development using the Playground Observation Checklist." Autism **11**(4): 311-319. | 2007 | Single Study: Sceening | elementary school children | autism, typical, MR | school | Playground Observation Checklist | observed for 15 min. during recess | children with autism distinguished from typical and MR by social problems; children with typical and MR did not differ in social competeny; four social behavs. On the checklist correctly ID 94% of children as having or not having autism; all children with autism and all typical were correctly classified | | | L2 | |
| 41 | Kobak, K. A., W. L. Stone, et al. (2011). "Web-based training in early autism screening: results from a pilot study." Telemed J E Health **17**(8): 640-644. | 2011 | Single Study: Sceening | | | | Screening Tool for Autism in Toddlers and Young Children | evaluates efficacy and acceptability of Web based training of the STAT as means of increasing accessibility to training | mean scores on STAT concepts significantly improved after taking tutorial | | | L2 | |

| # | Citation | Year | Type: Topic | Population/ Subpopulations | | Study Setting | Screening Tools/ Measures | Summary Notes | Results/Findings | Weighted Relevance | | | TEP Review |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 42 | Kopp, S. and C. Gillberg (2011). "The Autism Spectrum Screening Questionnaire (ASSQ)-Revised Extended Version (ASSQ-REV): an instrument for better capturing the autism phenotype in girls? A preliminary study involving 191 clinical cases and community controls." Res Dev Disabil **32**(6): 2875-2888. | 2011 | Single Study: Sceening | 6-16 years | ASD, ADHD, typical | | Autism Spectrum Screening Questionnaire (ASSQ); Autism Spectrum Screening Questionnaire Revised-GIRL | develop and validate an extension of ASSQ for better capturing female phenotype of ASD; compared on results of ASSQ and new set of items (ASSQ-GIRL) | ASSQ-REV discriminated well between cases and non-cases; certain single ASSQ-GIRL items were much more typical of girls than of boys with ASD (ex. avoids demands, determined, careless with phys. Appearance and dress) | | | L2 | |
| 43 | Landa, R. J., A. L. Gross, et al. (2012). "Latent class analysis of early developmental trajectory in baby siblings of children with autism." J Child Psychol Psychiatry. | 2012 | Single Study: Sceening | assess Mullen from 6-36 mo. | at risk-siblings of children w/ autism | p.c. | Mullen Scales of Early Learning | elucidate diversity and contour of early developmental trajectories exhibited by siblings of children with autism (sibs-A); Mullen t scores= dependent variables | 36 mo.- ASD (n=52); non-ASD social/communication delay (31); unaffected (121);; results support a category of ASD that involves slowing in early non-social development | | | L2 | |
| 44 | Matson, J. L. and M. Sipes (2010). "Methods of early diagnosis and tracking for autism and pervasive developmental disorder not otherwise specified (PDDNOS)." Journal of Developmental and Physical Disabilities **22**(4): 343-358. | 2010 | Single Study: Sceening | 17-37 mo. | | p.c. | Baby and Infant Screen for Children with Autism Traits-Part 1 (BISCUIT); Modified Checklist for Autism in Toddlers (M-CHAT); Personal-Social domain for Battelle Developmental Inventory Second Edition (BDI-2) | convergent and divergent validity of BISCUIT | BISCUIT-Part 1 demonsrated good convergent validity with M-CHAT and Personal Social domain from BDI-2; divergent validity demonstrated by small correlation with Adaptive and Motor domains from BDI-2 | | M2 | | |
| 45 | Mayes, S. D., S. L. Calhoun, et al. (2009). "Comparison of Scores on the Checklist for Autism Spectrum Disorder, Childhood Autism Rating Scale, and Gilliam Asperger's Disorder Scale for Children with Low Functioning Autism, High Functioning Autism, Asperger's Disorder, ADHD, and Typical Development." J Autism Dev Disord. | 2009 | Single Study: Sceening | | low/high functioning autism; ADHD | p.c. | Checklist for Autism Spectrum Disorder; Childhood Autism Rating Scale (CARS); Gillian Asperger's Disorder Scale (GADS) | reliability and validity for three autism instruments | children with LFA or ADHD- classification accuracy 100% for checklist and 98% for CARS clinician; children with HFA or ADHD, classification accuracy was 99% for checklist and 93% for GADS clinician; clinician-parent diagnostic agreement was high (90% checklist, 90% CARS, 84% GADS) | | M2 | | |

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|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 46 | McPartland, J. C., B. Reichow, et al. (2012). "Sensitivity and specificity of proposed DSM-5 diagnostic criteria for autism spectrum disorder." J Am Acad Child Adolesc Psychiatry **51**(4): 368-383. | 2012 | Single Study: Sceening | ASD (12 mo.-43 yr); non ASD (12 mo.-39 yr) | ASD; non-ASD | p.c. | individual field trial checklist items (e.g., nonverbal communication); checklist items grouped together as described by a single DSM-5 symptom (e.g., nonverbal and verbal communication); individual DSM-5 criterion (e.g., social-communicative impairment); and overall diagnostic criteria | evaluated potential impact of proposed DSM-5 diagnostic criteria for ASD | revised criteria impove specificity but excludes a substantial portion of cognitively able indv. and those with ASDs other than autistic disorder | | M2 | | |
| 47 | Nygren, G., E. Sandberg, et al. (2012). "A new screening programme for autism in a general population of Swedish toddlers." Res Dev Disabil **33**(4): 1200-1210. | 2012 | Single Study: Sceening | 2.5 year old | general | p.c. | Modified Checklist for Autism in Toddlers (M-CHAT); child's joing attention abilities (JA-OBS) | general population screening conducted at child health centres in Gothernburg, Sweden, efficacy of screening intruments in predicting clinical diagnosis of autism studied | Positive predictive value for the combination of M-CHAT and JA-OBS was 90%; combination shows promise for early detection of autism | H2 | | | |
| 48 | Oosterling, I. J., S. H. Swinkels, et al. (2009). "Comparative analysis of three screening instruments for autism spectrum disorder in toddlers at high risk." J Autism Dev Disord **39**(6): 897-909. | 2009 | Single Study: Sceening | mean 29.6 mo. | at risk | p.c. | Early Screening of Autistic Traits Questionnaire; Social Communication Questionnaire;, Communication and Symbolic Behavior Scales-Developmental Profile; Infant-Toddler Checklist; key items of the Checklist for Autism in Toddlers | discriminative properties are compared in the whole sample and in two age groups seperately (8-24mo. And 25-44 mo.) | Strictly speaking, not one single screening instrument investigated appears to meet standards for a satisfactory prediction of an ASD diagnosis in our high-risk sample of very young children, as no instrument demonstrates acceptable diagnostic accuracy for all four indices (Se, Sp, PPV, NPV), Balance between the sensitivity and specificity of the screens, as expressed by the AUCs, is fair at the most. None of the instruments performs clearly better than another in differentiating between ASD and non-ASD. However, it would be too simple and premature to dismiss all these instruments altogether, as each instrument shows specific strengths that should be considered in making decisions about which instrument to use for which purpose. | H2 | | | |

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|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 49 | Rodman, J. L., K. A. Gilbert, et al. (2010). "Efficacy of brief quantitative measures of play for screening for autism spectrum disorders." J Autism Dev Disord **40**(3): 325-333. | 2010 | Single Study: Sceening | 24-68 mo. | ASD | p.c. | brief quantitative measures:object exploration, diversity of play, turn taking | quick and effective screening measure; observe object exploration, diversity of play, turn taking | older children with ASD performed less turn taking; on all measures, IQ accounted for more of the difference between groups than diagnosis | | M2 | | |
| 50 | Scambler, D. J., S. L. Hepburn, et al. (2007). "A preliminary study of screening for risk of autism in children with fragile X syndrome: testing two risk cut-offs for the Checklist for Autism in Toddlers." J Intellect Disabil Res **51**(Pt 4): 269-276. | 2007 | Single Study: Sceening | 2-4 years | Fragile X; autism | home/school | Checklist for Autism in Toddlers (CHAT); modified risk criteria (i.e. The Denver Criteria) | CHAT and Denver compared in group of children with fragile X syndrome (FXS) and autism | CHAT: sensitivity 50%, specificity 100%; Denver: sensitivity 75%, specificity 92% | | M2 | | |
| 51 | Schanding, G. T., Jr., K. P. Nowell, et al. (2011). "Utility of the Social Communication Questionnaire-Current and Social Responsiveness Scale as Teacher-Report Screening Tools for Autism Spectrum Disorders." J Autism Dev Disord. | 2011 | Single Study: Sceening | school-aged children | | p.c. | Social Communication Questionnaire (SCQ); Social Responsiveness Scale (SRS) | examines use of SCQ and SRS as completed by parents and teachers | teacher completed SCQ and SRS yielded lower sensitivity and specificity than desirable; lowering cutoff scores on both improved sensitivity and specificity to more adequate levels | | | L2 | |
| 52 | Whitehouse, A. J., H. Coon, et al. (2010). "Narrowing the broader autism phenotype: a study using the Communication Checklist-Adult Version (CC-A)." Autism **14**(6): 559-574. | 2010 | Single Study: Sceening | | autism proband and parents | p.c. | Communication Checklist-Adult (CC-A) | investigate whether CC-A could identify subtypes of social and communication dysfunction in autism proband and their parents | CC-A proved sensitive to communication difficulties of autism probands and a proportion of their parents; majority of parents who demonstrated thebroader phenotype scored poorly on either Pragmatic Skills or Social Engagement scale only; social engagement scale particularly sensitive to difficutes of parents-social communicative passivity may be important part of broader autism phenotype | | M2 | | |
| 53 | Witwer, A. N. and L. Lecavalier (2007). "Autism screening tools: an evaluation of the Social Communication Questionnaire and the Developmental Behaviour Checklist-Autism Screening Algorithm." J Intellect Dev Disabil **32**(3): 179-187. | 2007 | Single Study: Sceening | school aged | | p.c. | Social Communication Questionnaire (SCQ); Developmental Bahviour Cheklist- Autism Screening Algorithm (DBC-ASA) | evaluate SCQ and DBC-ASA in same sample of school aged children with intellectual disability (ID) with and without PDDs | according to estb. cutoffs-SCQ sensitivity .92, specificity .62; DBC-ASA sensitivity .94, specificity .46 | | M2 | | |
| 54 | Yama, B., T. Freeman, et al. (2012). "Examination of the properties of the Modified Checklist for Autism in Toddlers (M-CHAT) in a population sample." J Autism Dev Disord 42(1): 23-34. | 2012 | Single Study: Screening | 20-67 mo. | unselected low risk sample | p.c. | Modified Checklist for Autism in Toddlers (M-CHAT) | examines max. age for screen administration, positive sreen rate in absence of follow-up telephone interviews, and distributional properties of positive screens of M-CHAT in an unselected low-risk sample | M-CHAT can be appropriately administered to children aged 20-48 mo;, documented explanations provided by mothers during screening appears to effectively ID potential screen misclassifications in absence of followup | H2 | | | |

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|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 55 | Kamp-Becker, I., M. Ghahreman, et al. (2011). "Evaluation of the revised algorithm of Autism Diagnostic Observation Schedule (ADOS) in the diagnostic investigation of high-functioning children and adolescents with autism spectrum disorders." Autism. | 2011 | Single Study: Sceening | 4-16 years | | | ADOS | analyze the predictive validity of different ASOS algorithms for module 3-particular for high functioning ASD | sensitivity was substantially higher for the newly developed 'revised algorithm' for both autism vs non spectrum, broader ASD vs. non spectrum, using the higher cut off | | M2 | | |
| 56 | Wall, D. P., J. Kosmicki, et al. (2012). "Use of machine learning to shorten observation-based screening and diagnosis of autism." Translational Psychiatry **2**. | 2012 | Single Study: Sceening | | | | ADOS-composed of four modules | used a series of machine-learning algorithms to study the complete set of scores from Module 1 of the ADOS | 8 of 29 items contained in Module 1 were sufficient to classify autism with 100% accuracy | | M2 | | |
| 57 | Baird, G. (2000). "A screening instrument for autism at 18 months of age: a 6-year follow-up study." J Am Acad Child Adolesc Psychiatry. | 2000 | Single Study: Screening | 18 mo.; addt'l screening at age 3, 5; follow up 7 | low risk; high risk | p.c. | CHAT; Checklist for Referral; Pervasive Developmental Disorders Questionnaire | | CHAT- sensitivity of 38%, specificity-98% for identifying childhood autism; positive predictive value of the instrument was maximized by concentration on the highest-risk group; repeated screening 1 mo. later increased the positive predictive value to 75% but reduced sensitivity to 20%, specificity close to 100% | H2 | | | |
| 58 | Glascoe, F. P. (2007). "Can a broadband developmental-behavioral screening test identify children likely to have autism spectrum disorder? Clin Pediatr 46(9). | 2007 | Single Study: Screening | 18-59 mo. | elevated risk scores on broadband screening (PEDS) | p.c. | Parents' Evaluation of Development Status (PEDS); Modified Checklist of Autism in Toddlers (M-CHAT) | Parents completed broadband screening (PEDS) and autism specific screen (M-CHAT) | of 427 children at risk on PEDS, 34% passed M-CHAT; to determine whether these potential overreferrals cold be reduced, parents' concerns on PEDS were used to predict M-CHAT results-->reduced overreferrals by 70% while maintaining high sensitivity (81%) | H2 | | | |
| 59 | Robins, D. L. (2008). "Screening for autism spectrum disorders in primary care settings." Autism **12**(5): 537-556. | 2008 | Review: Screening | | | p.c. | Broad developmental instruments: Parents' Evaluation of Developmental Status and the Ages and Stages Questionnaires; autism-specific tools: the Checklist for Autism in Toddlers, the Modified Checklist for Autism in Toddlers (M-CHAT) | Level of screening=type of sample:Level I-defined as an unselected sample, Level II- selected children already ID-ed as being at risk for developmental disorder; Breadth of Sample=range of difficultues the screening tools attempts to identify: broad screening instruments-ID multiple range of developmental difficulties, disorder specific tools-focus on single disorder or class of disorders | The development of the M-CHAT, a Level I and Level II screening instrument, is described, and current research and clinical use of the M-CHAT are reviewed, including description of the structured follow-up interview which reduces the false-positive rate of the parent-report M-CHAT | H2 | | | |

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|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 60 | Pinto-Martin, J. A., L. M. Young, et al. (2008). "Screening strategies for autism spectrum disorders in pediatric primary care." J Dev Behav Pediatr 29(5): 345-350. | 2008 | Single Study: Screening | 18-30 mo. | at risk | p.c. | Parents' Evalustion of Developmental Status (PEDS); Modified Checklist for Autism in Toddlers (M-CHAT) | compared number of children identified at risk for ASD at their well child visits between ages of 18-30 mo. Using PEDS and M-CHAT | ASSQ well suited as a general population screen, combining teacher and parent ASSQ and using cut off score of > or = 17 provided most efficient with sensitivity of .91 and specificity of ..86 | H2 | | | |
| 61 | Posserud, M. B., A. J. Lundervold, et al. (2009). "Validation of the autism spectrum screening questionnaire in a total population sample." J Autism Dev Disord 39(1): 126-134. | 2009 | Single Study: Screening | 7-9 year old | general | p.c. | Autism Spectrum Screening Questionnaire (ASSQ) | screen total population; high scorers invited for clinical assessment, along with large group of screen negative children | ASSQ well suited as a general population screen, combining teacher and parent ASSQ and using cut off score of > or = 17 provided most efficient with sensitivity of .91 and specificity of ..86 | | M2 | | |
| 62 | Wetherby, A. M., S. Brosnan-Maddox, et al. (2008). "Validation of the Infant-Toddler Checklist as a broadband screener for autism spectrum disorders from 9 to 24 months of age." Autism 12(5): 487-511. | 2008 | Single Study: Screening | 6-24 mo | general | health care/child care agencies | Infant Toddler Checklist; Systematic Observation of Red Flags for Autism (SORF) | review of research on accuracy of screeners for children with ASD that have been administered to general pediatric samples; present results of population based study with a broadband screener (ITC) to detect children with communication delays including children with ASD; methods- BROADBAND SCREEN w/ ITC; children with negative screen given developmental surveillance with ITC in three months until 24 mo. of age; children w/ positive screen or concerns on ITC given communication evaluation (CSBS behavior sample), developmental evaluation (Mullen Scales of Early Learning) , & autism specific screen (SORF) | positive and negative predictive values support the validity of ITC for children 9-24 mo. Of age but not 6-8 mo;of 60 children diagnosed w/ ASD 56 had positive screen on ITC; parent concern increased with child age from less than half reporting concern from 6-15 mo. and nearly three fourths at 21-24 mo. | H2 | | | |
| 63 | Sices, L., T. Stancin, et al. (2009). "PEDS and ASQ developmental screening tests may not identify the same children." Pediatrics 124(4): e640-647. | 2009 | Single Study: Sceening | 9-31 mos., mean 17.6 | | p.c. | PEDS, ASQ | Substantial discrodance between PEDS & ASQ | | H2 | | | |
| 64 | Stone, W. L., C. R. McMahon, et al. (2008). "Use of the Screening Tool for Autism in Two-Year-Olds (STAT) for children under 24 months: an exploratory study." Autism **12**(5): 557-573. | 2008 | Single Study: Screening | 12-23mo. | at risk-had older sibling with ASD, been referred for evaluation | p.c. | Screening Tool for Autism in Two-Year-Olds (STAT) | receive STAT between 12-23 mo. Of age and follow up diagnostic evaluation after 24 mo.- all had older sibiling with ASD or been referred for evaluation for concerns about autism | sensitivity .95, specificity .73, positive predictive value-.56, negative predicitve value-.97; false positive highest for 12-13 month old group; STAT screening improved when sample limited to children 14 mo. and older | | M2 | | |
| 65 | van Daalen, E., C. Kemner, et al. (2009). "Inter-rater reliability and stability of diagnoses of autism spectrum disorder in children identified through screening at a very young age." Eur Child Adolesc Psychiatry 18(11): 663-674. | 2009 | Single Study: Sceening | screening process-around 14 mo./ diagnoses at 23 mo.and 42 mo. | | p.c. | | examine inter-rater reliability and stability of ASD diagnoses made at a very early age | interrated reliability on diagnosis of ASD vs. non ASD at 23 mo. was 87%; most diagnostic changes at 42 mo. Were within the autism spectrum from autistic disorder to PDD-NOS mainly due to diminished symptom severity | H2 | | | |

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|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 66 | Kleinman, J. M., D. L. Robins, et al. (2008). "The modified checklist for autism in toddlers: a follow-up study investigating the early detection of autism spectrum disorders." J Autism Dev Disord 38(5): 827-839. | 2008 | Single Study: Screening | 16-26.9 mo. | general | p.c. | M-CHAT; M-CHAT Follow Up Interview | used M-CHAT and M-CHAT follow up interview to screen 4797 children during toddler checkups | of 4797 cases- 466 screened positive on M-CHAT; of the 362 who completed the follow-up interview, 61 continued to show risk for ASDs; total of 41 children have been evaluated; 21 children have been diagnosed with ASD, 17 were classified with non-ASD delays, three were typically developing; PPV of M-CHAT plus follow up was .57; only 4 of the 21 cases of ASD were flagged by pediatrician | H2 | | | |
| 67 | Hix-Small, H., K. Marks, et al. (2007). "Impact of implementing developmental screening at 12 and 24 months in a pediatric practice." Pediatrics 120(2): 381-389. | 2007 | Single Study: Screening | 12-24 mos. | General (those with identified delays excluded) | p.c. | ASQ (54% completion rate) | | ASQ & Pediatric Developmental Impression results differed significantly (agreement = 81.8) | H2 | | | |
| 68 | Warren, Z., W. Stone, et al. (2009). "A training model for the diagnosis of autism in community pediatric practice." J Dev Behav Pediatr 30(5): 442-446. | 2009 | Single Study: Practitioner Training | | | p.c. | ASD-specific | small, targeted group of community pediatricians participated in an intensive training, conducted specialized ASD evaluations within their own practices, and then referred a consecutive series of children to a medical center diagnostic clinic for an independent assessment of ASD | indicate good agreement (71%) between pediatrician judgments and independent diagnostic ASD evaluations, but a significant trend toward overidentification when a diagnostic decision is forced | H2 | | | |
| 69 | Allely, C. S. and P. Wilson (2011). "Diagnosing autism spectrum disorders in primary care." Practitioner 255(1745): 27-30, 23 | 2011 | Report: Screening | | | p.c. | | WHAT are the diagnostic criteria for ASD? HOW should children be assessed? WHICH patients should be referred? Lists risk factors for ASD and assessment tools | The evidence for developmental benefits of early intervention in ASD is largely based on observational studies. Overall, evidence supporting the use of autism-specific diagnostic tools, either individually or in combination, is poor, so the clinical benefits of using these tools remain uncertain. The NICE guidelines nevertheless acknowledged that both an autism-specific semistructured interview and observation are effective in implementing a structured means of collating information to aid diagnostic assessment. M-CHAT can be used for assessment of young children in primary care by GPs or health visitors when ASD is suspected. They can identify clinical features indicative of increased risk but should not be used to rule out ASD.*^ M-CHAT is a promising instrument for the early detection of ASD. It fails to recognize 15% of children with the condition. | H3 | | | |
| **Studies/Reviews of Actual Provider Practices & Attitudes and/or of Screening Implementation Projects** | | | | | | | | | | | | | |
| 70 | Gura, G. F., M. T. Champagne, et al. (2011). "Autism spectrum disorder screening in primary care." J Dev Behav Pediatr 32(1): 48-51. | 2011 | Single Study: Screening | 18, 24 mo. | general population | p.c. | Modified Checklist for Autism in Toddlers (M-CHAT) | examines whether private primary care practice could overcome screening barriers and implement the universal ASD screening practice using M-CHAT; practice change developed- retrospective chart review of 99 subjects was done to evaluate screening fidelity and cost | overall screening fidelity of 91% achieved over 7 mo. Period; cost of screening avg $22.78/mo.- offset by avg. $38.76 of revenue/mo. | H2 | | | |

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|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 71 | Self, T. L., K. Coufal, et al. (2010). "Allied healthcare providers' role in screening for autism spectrum disorders." J Allied Health 39(3): 165-174 | 2010 | Single Study: Screening | | | p.c. | | surveyed allied health care providers to determine whether they received training on characteristics of ASD and ASD specific screening strategies through their pre-professional education or continuing education; asked about reposibility for screening children with ASD in their workplace and what would help them be better prepared | Speech language pathologists (SLPs) and Occupational therapists (Ots) reported received more training than physical therapists (PTs) and physicians assistants(PAs) | | | L2 | |
| 72 | Nadel, S. and J. E. Poss (2007). "Early detection of autism spectrum disorders: screening between 12 and 24 months of age." J Am Acad Nurse Pract 19(8): 408-417. | 2007 | Review: Screening | 12-24 mo. | | p.c. | | present NPs with info on screening for ASDs in children between 12-24 mo.; rec. provided for appropriate referrals and initiation of early intervention | | | M1 | | |
| 73 | Miller, J. S. (2011). "The Each Child Study: Systematic Screening for Autism Spectrum Disorders in a Pediatric Setting." Pediatrics. | 2011 | Single Study: Screening | 14-30 mo. | general | p.c. | M-CHAT; ITC | investigate feasibility and outcome of systematic autism screening process for all toddlers in large community based pediatric practice; | of those screened- 3 already been diagnosed with ASD,, 10 showed signs of early ASD; formal screening measures identified more children with ASD than clinical judgement/caregiver concern | H2 | | | |
| 74 | Kobak, K. A., W. L. Stone, et al. (2011). "Web-based training in early autism screening: results from a pilot study." Telemed J E Health **17**(8): 640-644. | 2011 | Single Study: Sceening | | | | Screening Tool for Autism in Toddlers and Young Children | evaluates efficacy and acceptability of Web based training of the STAT as means of increasing accessibility to training | mean scores on STAT concepts significantly improved after taking tutorial | | | L2 | |
| 75 | Gillis, J. M. (2009). "Screening Practices of Family Physicians and Pediatricians in 2 Southern States." Infants & Young Children 22(4). | 2009 | Single Study: Sceening | | | p.c. | DD & ASD tools | | High rates of DD screening but only 28% for ASD | H2 | | | |
| 76 | Radecki, L., N. Sand-Loud, et al. (2011). "Trends in the use of standardized tools for developmental screening in early childhood: 2002-2009." Pediatrics 128(1): 14-19. | 2011 | Single Study: Sceening | <36 mos. | | p.c. | DD tools | | <50% used standardized DD screening tools | H2 | | | |
| 77 | Carbone, P. S., D. D. Behl, et al. (2010). "The medical home for children with autism spectrum disorders: parent and pediatrician perspectives." J Autism Dev Disord 40(3): 317-324. | 2009 | Single Study: Perceptions of Parents vs. Ped | 5-14 years | | p.c. | | examines differences btwn. perceptions of parents and pediatricians regarding the need of children w/ ASD and their families within the medical home | parent perceived physicians did not act early upon their concerns about development and care is less comprehensive, coordinated and family-centered; pediatricians desire to impove services but cite lack of time, training and resources as barriers | H2 | | | |
| 78 | Caronna, E. B., M. Augustyn, et al. (2007). "Revisiting parental concerns in the age of autism spectrum disorders: the need to help parents in the face of uncertainty." Arch Pediatr Adolesc Med 161(4): 406-408. | 2007 | Review:Parental Concerns | | | p.c. | | | recommendations: acknowledge parents' concerns, provide simple parenting strategies to enhance parental understanding of the child, give parents information about what is to be watched and during what period of time; see parents through the process | | | L3 | |

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|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 79 | Hix-Small, H., K. Marks, et al. (2007). "Impact of implementing developmental screening at 12 and 24 months in a pediatric practice." Pediatrics 120(2): 381-389. | 2007 | Single Study: Screening | 12-24 mos. | General (those with identified delays excluded) | p.c. | ASQ (54% completion rate) | | ASQ & Pediatric Developmental Impression results differed significantly (agreement = 81.8) | H2 | | | |
| 80 | McGookin, E. and V. D'Sa (2011). "Developmental screening in a pediatric care practice." Med Health R I 94(7): 194-196. | 2011 | Single Study: Screening | 9, 15, 18, 24 mo. | general | p.c. | PEDS, M-CHAT | | retrospective study revealed that while PEDS and M-CHAT can be routinely used in busy private practice- clinicians did not strctly adhere to the referral criteria for the screening tools | H2 | | | |
| 81 | Murray, K.E. "Emotional Behavioral Screening by Primary Care Practitioners: Attitudes, Practices, and Barriers | | Single Study: Pediatricians' attitudes | | | p.c. | Emotional Behavioral Screening Survey | assess specific techniques and instruments primary care pediatricians and family practitioners use to detect emotional and behavioral problem and describe their beliefs about the prevalence of these problems and barriers to universal screening | Nearly one in three participants (30%) endorsed use of a standardized, validated tool for broad developmental screening. However, consistent, universal use of these tools was endorsed by only one in fifty (2.6%). Use of standardized tools targeting emotional and behavioral problems is less common with 11% using these tools at least some of the time and only one participant (0.37%) who reported using them universally and consistently; Barriers most commonly endorsed by our respondents included lack of time (93%), lack of training in use of appropriate screening tools (88%), lack of mental health providers (79%), and lack of adequate personnel (77%). | H2 | | | |
| 82 | Earls, M. F., J. E. Andrews, et al. (2009). "A longitudinal study of developmental and behavioral screening and referral in North Carolina's Assuring Better Child Health and Development participating practices." Clin Pediatr (Phila) 48(8): 824-833. | 2009 | Single Study: Screening | 6-60 mos. | general | p.c. | Ages & Stages Questionnaire @ 6,12,18,24,36,48,60 mos | determine the number of children who were screened and whether this rate improved with time, observe patterns and trajectories for children identified at risk in 1 or more of the 5 developmental domains, and examine referral rates and physician referral patterns. | The number of screenings per child increased over the first 2 to 2½ years of the project, as reflected in the increasing rate of screening in the younger versus the older subgroups of the cohort. The pro- viders and practices improved in their implementa- tion of the process over time. Even in these first years of the project, a substantial increase in child find rate was seen as compared with the rest of the state. It is of particular note that more children were also referred at an earlier age, optimizing the participation in early intervention | H2 | | | |
| **Screening Frequency** | | | | | | | | | | | | | |
| 83 | Barbaro, J. and C. Dissanayake (2009). "Autism spectrum disorders in infancy and toddlerhood: a review of the evidence on early signs, early identification tools, and early diagnosis." J Dev Behav Pediatr 30(5): 447-459 | 2009 | Review: Screening | | | p.c. | | Recommend monitor behavior over time | The prevalent finding from studies on autism spec- trum disorders (ASDs) in infancy and toddlerhood is that abnormalities in social attention and communication be- haviors are evident from the first year of life and are the most predictive early signs of an ASD diagnosis; The routine and repeated monitoring of behaviors throughout the infancy period, rather than a single screening at a given age, may prove more useful in detecting ASDs in infancy | H1 | | | |
| 84 | Earls, M. F., J. E. Andrews, et al. (2009). "A longitudinal study of developmental and behavioral screening and referral in North Carolina's Assuring Better Child Health and Development participating practices." Clin Pediatr (Phila) 48(8): 824-833. | 2009 | Single Study: Screening | 6-60 mos. | general | p.c. | Ages & Stages Questionnaire @ 6,12,18,24,36,48,60 mos | determine the number of children who were screened and whether this rate improved with time, observe patterns and trajectories for children identified at risk in 1 or more of the 5 developmental domains, and examine referral rates and physician referral patterns. | The number of screenings per child increased over the first 2 to 2½ years of the project, as reflected in the increasing rate of screening in the younger versus the older subgroups of the cohort. The providers and practices improved in their implementa- tion of the process over time. Even in these first years of the project, a substantial increase in child find rate was seen as compared with the rest of the state. It is of particular note that more children were also referred at an earlier age, optimizing the participation in early intervention | H2 | | | |

| # | Citation | Year | Type: Topic | Population/ Subpopulations | | Study Setting | Screening Tools/ Measures | Summary Notes | Results/Findings | Weighted Relevance | | | TEP Review |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 85 | Landa, R. J. (2008). "Diagnosis of autism spectrum disorders in the first 3 years of life." Nat Clin Pract Neurol 4(3): 138-147. | 2008 | Review: General-Screening | 0-3 years | | p.c | | focuses on early detection and intervention | Screening for ASDs should begin by 18 months of age and be repeated at 24 and 36 months of age; diagnosis of ASD becomes increasingly stable over the first 3 years of life. Detection of an ASD- related behavioral profile is possible as early as the first birthday and warrants enrollment in an intervention. | H1 | | | |
| 86 | Kleinman, J. M., D. L. Robins, et al. (2008). "The modified checklist for autism in toddlers: a follow-up study investigating the early detection of autism spectrum disorders." J Autism Dev Disord 38(5): 827-839. | 2008 | Single Study: Screening | 16-26.9 mo. | general | p.c. | M-CHAT; M-CHAT Follow Up Interview | used M-CHAT and M-CHAT follow up interview to screen 4797 children during toddler checkups | of 4797 cases- 466 screened positive on M-CHAT; of the 362 who completed the follow-up interview, 61 continued to show risk for ASDs; total of 41 children have been evaluated; 21 children have been diagnosed with ASD, 17 were classified with non-ASD delays, three were typically developing; PPV of M-CHAT plus follow up was .57; only 4 of the 21 cases of ASD were flagged by pediatrician | H2 | | | |
| **Age to Start** | | | | | | | | | | | | | |
| 87 | Barbaro, J. and C. Dissanayake (2009). "Autism spectrum disorders in infancy and toddlerhood: a review of the evidence on early signs, early identification tools, and early diagnosis." J Dev Behav Pediatr 30(5): 447-459 | 2009 | Review: Screening | | | p.c. | | Recommend monitor behavior over time | The prevalent finding from studies on autism spectrum disorders (ASDs) in infancy and toddlerhood is that abnormalities in social attention and communication behaviors are evident from the first year of life and are the most predictive early signs of an ASD diagnosis; The routine and repeated monitoring of behaviors throughout the infancy period, rather than a single screening at a given age, may prove more useful in detecting ASDs in infancy | H1 | | | |
| 88 | Crais, E. R., L. R. Watson, et al. (2006). "Early identification of autism: how early can we go?" Semin Speech Lang **27**(3): 143-160. | 2006 | Review: Screening | | | p.c. | | Skill areas with particular promise for early identification include social communication, sensory regulation, and play; article previews current innovative methodologies, presents a synthesis of recent research findings related to thse three areas; provides clinicians with practical guidelines for early ID of infants/toddlers at risk for ASD and other disorders | | H1 | | | |
| 89 | Twyman, K. A. (2008). "Parents' developmental concerns and age variance at diagnosis of children with autism spectrum disorder. | 2009 | Single Study: Sceening | | ASD | home | Parent concerns | Parent concerns re: social development domain at earlier ages associated with earlier Dx | | | M2 | | |
| 90 | Stone, W. (2008). "Use of the Screening Tool for Autism in Two Year Olds (STAT) for children under 24 months: An exploratory study." Autism. | 2008 | Single Study: Sceening | <24 mos. | High Risk | p.c. | STAT at 12-23, Dx eval at 24 | | se .95, sp .73, PPV .56, NPV .97 | | M2 | | |
| **Studies at or under age 2** | | | | | | | | | | | | | |
| 91 | Charman, T. and G. Baird (2002). "Practitioner review: Diagnosis of autism spectrum disorder in 2- and 3-year-old children." J Child Psychol Psychiatry 43(3): 289-305. | 2002 | Review: Screening | 2, 3 year | | | | A selective review of recent research literature on the characteristic features of ASD in pre- school children. | Earlier diagnosis and rising recognition of ASD have significant implications for primary healthcare and specialist diagnostic and therapeutic services. | H1 | | | |

| # | Citation | Year | Type: Topic | Population/ Subpopulations | | Study Setting | Screening Tools/ Measures | Summary Notes | Results/Findings | Weighted Relevance | | | TEP Review |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 92 | Bryson, S. E., L. Zwaigenbaum, et al. (2008). "The Autism Observation Scale for Infants: Scale development and reliability data." Journal of Autism and Developmental Disorders Vol.38(4): pp. | 2008 | Single Study: Sceening | 6, 12, 18 mo. | high risk | p.c. | | describe the AOSI and its development, and provide preliminary data on its reliability | inter-rater reliability both for total scores and total number of endorsed items is good to excellent at 6, 12 and 18 months; reliability is more modest for individual items, particularly in 6-month-olds. Test-retest reliability of the AOSI at 12 months of age is within acceptable limits | | M2 | | |
| 93 | Zwaigenbaum, L., S. Bryson, et al. (2009). "Clinical assessment and management of toddlers with suspected autism spectrum disorder: insights from studies of high-risk infants." Pediatrics 123(5): 1383-1391. | 2009 | Review: Screening | under age 2 | | | | review of findings from recent studies on early development of children with ASD, summarizing current knowledge on early signs of ASD, screening properties of early detection tools, current best practice for ASD before 2 years of age | ASD-specific screeners can potentially identify toddlers with ASD who are not flagged by either parents or clinicians in a general surveillance context. Need to reduce the time between initial emergence of ASD symptoms and referral for specialized assessments. For those under 2, need to assess social & communication development using both direct observation & parent report. Under 2 years old, often difficult to differentiate ASD sxs from other types of DD. Mild/absence of sxs at 18 mos. do not r/o ASD so on-going surveillance & follow-up are essential. Few studies of stability of ASD dx when dx before age 2. Dx after age 2 tends to be stable. Positive screener/concerns should be followed by audiologic testing. | H1 | | | |
| 94 | Chawarska, K., A. Klin, et al. (2007). "Autism spectrum disorder in the second year: stability and change in syndrome expression." J Child Psychol Psychiatry 48(2): 128-138. | 2007 | Single Study: Sceening | under age 2 | | p.c. | | examined 1) the symptoms of ASD in the second year and changes in the syndrome expression by the age of three; 2) relationship between expert-assigned clinical diagnosis and diagnostic classification based on Autism Diagnostic Observation Schedule-Generic (ADOS-G) and Autism Diagnostic Interview- Revised (ADI-R) in the second year; 3) the relationship between direct observation and parental report of ASD symptoms | provides support for stability of clinical diagnosis and syndrome expression in the second year and highlights advantages and limitations of the ADI-R and ADOS-G for diagnosing and documenting symptoms of ASD in infants | | M2 | | |
| 95 | Glascoe, F. P. and J. Squires (2007). "Issues with the new developmental screening and surveillance policy statement." Pediatrics 119(4): 861-862; discussion 862-863. | 2007 | Review: Screening | | | | | | Although compliance with the American Academy of Pediatrics recommendations for both broadband and autismspecific screening at 18 and 24 months is still recommended, viewing performance patterns on a broadband screening test can substantially reduce overreferrals to autism specialty services.<br>Waiting lists for diagnostic evaluations of a year or more are not uncommon. Although non-ASD specialists can administer autism-specific screens, primary care providers struggle to administer even a single broadband screen—adding a second measure may be prohibitive in terms of time and reimbursement. A more parsimonious solution to identifying possible ASD was found by viewing individual items on broadband screening, in this case, unique patterns of parental concerns. Broadband screening followed by an autism-specific tool is more accurate in determining the need for referral to an autism specialist than is a broadband screen alone. But, providers who are unable to administer an autism-specific screen can make use of patterns of parental concerns on broadband screening to decide when referrals to autism specialists are needed | | M3 | | |

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|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 96 | Ozonoff, S., G. S. Young, et al. (2009). "How early do parent concerns predict later autism diagnosis?" Journal of Developmental and Behavioral Pediatrics Vol.30(5): pp. | 2009 | Single Study: Sceening | 6, 12, 18; follow up 36 mo. | | home/p.c. | | parents were asked about developmental concerns at study intake and when their infant was 6, 12, and 18 months. Infants were then followed up until 36 months, when diagnostic status was determined. | By the time their child was 12 months, parents who have an older child with autism reported significantly more concerns in autism spectrum disorders-related areas than parents of children with typical outcomes. These concerns were significantly related to independent measures of developmental status and autism symptoms and helped predict which infants would later be diagnosed with autism or autism spectrum disorders. At 6 months, however, the concerns of parents who have an older child with autism do not predict outcome well. | H2 | | | |
| 97 | Nadel, S. and J. E. Poss (2007). "Early detection of autism spectrum disorders: screening between 12 and 24 months of age." J Am Acad Nurse Pract 19(8): 408-417. | 2007 | Review: Screening | 12-24 mo. | | p.c. | | present nurse practitioners (NPs) with information on screening for autism spectrum disorders (ASDs) in children between 12 and 24 months of age. Recommendations are also provided for appropriate referrals and initiation of early intervention (EI). | Children with ASD exhibit impaired social interaction, verbal and nonverbal communication deficits, and repetitive, restricted, and stereotyped patterns of behavior or interests. Studies show that these children benefit from beginning intensive EI as soon as possible. | | M1 | | |
| 98 | Barbaro, J. and C. Dissanayake (2009). "Autism spectrum disorders in infancy and toddlerhood: a review of the evidence on early signs, early identification tools, and early diagnosis." J Dev Behav Pediatr 30(5): 447-459. | 2009 | Review: Screening | | | | | | recommended that future prospective studies monitor behavior repeatedly over time, thereby increasing the opportunity to identify early manifestations of ASD and facilitating the charting of subtle behavioral changes that occur in the development of infants and toddlers with ASD. | H1 | | | |
| 99 | Barbaro, J. and C. Dissanayake (2010). "Prospective identification of autism spectrum disorders in infancy and toddlerhood using developmental surveillance: the social attention and communication study." J Dev Behav Pediatr 31(5): 376-385. | 2010 | Single Study: Sceening | 8, 12, 18, 24 mo. | at risk | p.c. | | | A total of 216 children were referred, with 110 being further assessed. Of these, 89 children were classified with an ASD at 24 months, and 20 children had developmental and/or language delays, resulting in a Positive Predictive value of 81%. The estimated rate of ASDs in the Social Attention and Communication Study cohort ranged from 1:119 to 1:233 children. Estimated sensitivity ranged from 69% to 83.8%, and estimated specificity ranged from 99.8% to 99.9% | H2 | | | |
| 100 | Pierce, K., C. Carter, et al. (2011). "Detecting, studying, and treating autism early: the one-year well-baby check-up approach." J Pediatr 159(3): 458-465 e451-456. | 2011 | Single Study: Sceening | 12-24 mo. | | p.c. | | The Communication and Symbolic Behavior Scales Developmental Profile Infant-Toddler Checklist was distributed at every 1-year pediatric check-up; 137 pediatricians and 225 infants participated. Screens were scored immediately, and failures referred for further evaluation | Pediatricians screened 10 479 infants at the 1-year check-up; 184 infants who failed the screen were evaluated and tracked. To date, 32 infants received a provisional or final diagnosis of ASD, 56 of LD, nine of DD, and 36 of ‘‘other.’’ Five infants who initially tested positive for ASD no longer met criteria at follow-up. The remainder of the sample was false positive results. Positive predictive value was estimated to be .75. | H2 | | | |
| 101 | Brian, J., S. E. Bryson, et al. (2008). "Clinical assessment of autism in high-risk 18-month-olds." Autism Vol.12(5): | 2008 | Single Study: Sceening | 18 mo. | ASD sibs, non-ASD sibs, controls | p.c. | Autism Diagnostic Observation Schedule (ADOS); Autism Observation Scale for Infants (AOSI) | | majority of informative ADOS items came from the social and behavioural domains, and AOSI items measuring behavioural reactivity and motor control contributed additional information. | | M2 | | |

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| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 102 | Baird, G., T. Charman, et al. (2000). "A screening instrument for autism at 18 months of age: a 6-year follow-up study." J Am Acad Child Adolesc Psychiatry **39**(6): 694-702. | 2000 | Single Study: Sceening | 18mo. -->3 yrs-->5 yrs-->7 yr | | p.c. | Checklist for Autism in Toddlers (CHAT) | 18 mo.-brief checklist assessinng joint attention and pretend play behaviors; 2-stage screening process; those who failed stage 1, re-screened by phone 1 month later. follow up methods through parents/health practitioners/medical and educational records | PPV for high & medium risk using 2-stage was 59%, but sensitivity was low - 2 stage 21% se, 1 stage 35% se | H2 | | | |
| **Studies including referral practices** | | | | | | | | | | | | | |
| 103 | Earls, M. F., J. E. Andrews, et al. (2009). "A longitudinal study of developmental and behavioral screening and referral in North Carolina's Assuring Better Child Health and Development participating practices." Clin Pediatr (Phila) 48(8): 824-833. | 2009 | Single Study: Screening | 6-60 mos. | general | p.c. | Ages & Stages Questionnaire @ 6,12,18,24,36,48,60 mos | determine the number of children who were screened and whether this rate improved with time, observe patterns and trajectories for children identified at risk in 1 or more of the 5 developmental domains, and examine referral rates and physician referral patterns. | The number of screenings per child increased over the first 2 to 2 1⁄2 years of the project, as reflected in the increasing rate of screening in the younger versus the older subgroups of the cohort. The pro- viders and practices improved in their implementa- tion of the process over time. Even in these first years of the project, a substantial increase in child find rate was seen as compared with the rest of the state. It is of particular note that more children were also referred at an earlier age, optimizing the participation in early intervention | H2 | | | |
| 104 | McGookin, E. and V. D'Sa (2011). "Developmental screening in a pediatric care practice." Med Health R I 94(7): 194-196. | 2011 | Single Study: Screening | 9, 15, 18, 24 mo. | general | p.c. | PEDS, M-CHAT | | retrospective study revealed that while PEDS and M-CHAT can be routinely used in busy private practice- clinicians did not strctly adhere to the referral criteria for the screening tools | H2 | | | |
| 105 | Ming, X., A. Hashim, et al. (2011). "Access to specialty care in autism spectrum disorders-a pilot study of referral source." BMC Health Serv Res 11: 99. | 2011 | Single Study: Referral | | ASD Dx vs. non-ASD neurological condition | p.c. | | Parent reported “source of referral” and “reason for the referral” of 189 ASD children and 108 non-ASD neurological disordered children were analyzed. | Majority of children's parents' did not indicate they had primary care referral; referral % lower for ASD vs non-ASD | H2 | | | |
| 106 | Tsakanikos, E., P. Sturmey, et al. (2007). "Referral trends in mental health services for adults with intellectual disability and autism spectrum disorders." Autism 11(1): 9-17. | 2006 | Single Study: Referral | | | | | examined patterns of change in referral trends to specialist mental health services | significant change in rate of referrals, ad increase in diagnosable psychiatric disorders over time and a significan reduction of medication at time of referral; no significant changes in therapeutic interventions | | M2 | | |
| 107 | **How to track outcomes; Physician Follow-up** | | | | | | | | | | | | |
| 108 | Magiati, I., J. Moss, et al. (2011). "Is the Autism Treatment Evaluation Checklist a useful tool for monitoring progress in children with autism spectrum disorders?" J Intellect Disabil Res **55**(3): 302-312. | 2011 | Single Study: Sceening | avg-5.5 years/ follow up 10.4 | ASD | p.c. | Autism Treatment Evaluation Checklist (ATEC) | | ATEC high internal consistency at both time points; total and subscores remained relatively stable and high correlated with cogn., lang., adaptive behav. skills and severity of autism symptoms | H2 | | | |
| 108a | Inglese, M. D. (2009). "Caring for children with autism spectrum disorder. Part II: screening, diagnosis, and management." J Pediatr Nurs 24(1): 49-59. | 2009 | Review: Screening | infants + toddlers < 3 years | | p.c. | | reviews screening and diagnosis; infants and toddlers development, and ASD; treatment and ongoing management | the Autism Behavior Checklist (ABC) has not been particularly helpful in screening or diagnosis, but it is helpful in tracking changes in a child already having an autism spectrum diagnosis. The ABC is thus also useful when monitoring treatment responses | | M1 | | |

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| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 109 | Earls, M. F., J. E. Andrews, et al. (2009). "A longitudinal study of developmental and behavioral screening and referral in North Carolina's Assuring Better Child Health and Development participating practices." Clin Pediatr (Phila) 48(8): 824-833. | 2009 | Single Study: Screening | 6-60 mos. | general | p.c. | Ages & Stages Questionnaire @ 6,12,18,24,36,48,60 mos | determine the number of children who were screened and whether this rate improved with time, observe patterns and trajectories for children identified at risk in 1 or more of the 5 developmental domains, and examine referral rates and physician referral patterns. | The number of screenings per child increased over the first 2 to 21⁄2 years of the project, as reflected in the increasing rate of screening in the younger versus the older subgroups of the cohort. The pro- viders and practices improved in their implementation of the process over time. Even in these first years of the project, a substantial increase in child find rate was seen as compared with the rest of the state. It is of particular note that more children were also referred at an earlier age, optimizing the participation in early intervention | H2 | | | |
| | **Review Studies Including Treatment** | | | | | | | | | | | | |
| 110 | Boyd, B. A., S. L. Odom, et al. (2010). "Infants and toddlers with autism spectrum disorder: Early identification and early intervention." Journal of Early Intervention Vol.32(2): pp. | 2010 | Review: Screening & Treatment /Intervention | 0-3 years | | p.c. | | summarize current scientific and policy information on early identification and early inter- vention for infants and toddlers with ASD and their families | reviews current scientific and policy information on early identification and early intervention for infants and toddlers with ASD and their families; includes tables outlining interventions | | M1 | | |
| 111 | Myers, S. S., Johnson, C. P. (2007). "Management of Children with Autism Spectrum Disorders." Journal of American Academy of Pediatrics. | 2007 | Review-Treatment | young/older children and adolescents | | p.c | | reviews educational strategies and associated therapies that are primary treatments for children with autism | There is a growing body of evidence that supports the efficacy of certain interventions in ameliorating symptoms and enhancing functioning, but much remains to be learned. In addition to their impor tant roles in identifying ASDs through screening and surveillance, establishing the diagnosis, conducting an etiologic evaluation, and providing genetic counseling after a diagnosis is made, pediatricians and other primary health care professionals are in a position to provide important longitudinal medical care and to support and educate families and guide them to empirically supported interventions for their children | H1 | | | |
| 112 | Carr, J. E. and L. A. LeBlanc (2007). "Autism spectrum disorders in early childhood: an overview for practicing physicians." Prim Care 34(2): 343-359 | 2007 | Review-General-Treatment | < 3 yr | | p.c | | includes screening/diagnosis but mostly about treatment | recommends phsyicians adopt universal screening practices and evaluate parental reports rather liberally; establish relationship with local diagnosticians can help expedite the diagnostic process for families; make recommendations/referrals for treatment informed by available empiric support; educate patients and families about comorbid medical problems | | M1 | | |
| 113 | Lindgren, S. (2008). "Evidence Based Interventions for Autism Spectrum Disorder." | 2008 | Review-General-Treatment | | | p.c | | includes screening/diagnosis but mostly about treatment | early autism treatment:primary focus should be on the child's acquisition of communication, social, play, and academic skills; medication cannot cure but can help provide control over some symptoms | H1 | | | |
| | **General Reviews** | | | | | | | | | | | | |
| 114 | de L. Martinez-Pedraza, F. and A. S. Carter (2009). "Autism spectrum disorders in young children." Child and Adolescent Psychiatric Clinics of North America Vol.18(3): pp. | 2009 | Review: General | 0-5 years | | p.c | | reviews early signs and symptoms of ASD, describe some of the measures that can be employed for screening and diagnosis, discuss the family context with respect to both adaptation to diagnosis and treatment, and conclude with brief review of interventions for young children with ASD | Advocate the use of broader first-stage screeners at the population level that target language and/or developmental functioning (e.g., Ages and Stages Questionnaire ASQ, Infant Toddler Checklist), paired with a social-emotional-behavioral problem screener (e.g. ASQ-Social Emotional, Brief Infant Toddler Social Emotional Assessment) rather than employing autism-specific level 1 screeners; Need to determine the specificity of broader screeners in detecting ASD – must use a broader screener that includes items that are specific red flags for ASD. Given time pressures, should use a single tool that can detect a wide range of problems at the earliest possible stages. If screen positive, then determine whether to do level 2 ASD screener, refer to specialist, etc. | H1 | | | |

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| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 115 | Council on Children With, D., P. Section on Developmental Behavioral, et al. (2006). "Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening." Pediatrics 118(1): 405-420. | 2006 | Review: General-Screening | 0-3 years | | p.c | | | recommend developmental surveillance be incorporated into every well-child preventive care visit; any concerns raised should be addressed with standardized dev. screening tests; screening tests should be administered regularly at 9, 18, 30 mo. visits | H1 | | | |
| 116 | Carbone, P. S., M. Farley, et al. (2010). "Primary care for children with autism." Am Fam Physician 81(4): 453-460. | 2010 | Review: General | | | p.c | | general review on screening/diagnosis/treatment | Evidence shows that early treatment is beneficial; therefore, early diagnosis of autism is critical. Physicians who routinely perform developmental surveillance and use appropriate screening tools increase the chances of an early diagnosis | H1 | | | |
| 117 | Filipek, P. A., P. J. Accardo, et al. (2000). "Practice parameter: screening and diagnosis of autism: report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society." Neurology 55(4): 468-479. | 2000 | Review: Screening | | | p.c. | | reviews the available empirical evidence and gives specific recommendations for the identification of children with autism. Identifying children with autism and initiating intensive, early intervention during the preschool years results in improved outcomes for most young children with autism. | (CHAT) for 18-month-old infants, and the Autism Screening Questionnaire for children 4 years of age and older, have been validated on large populations of children. However, it should be noted that the CHAT is less sensitive to milder symptoms of autism, as children later diagnosed with PDD-NOS, Asperger's, or atypical autism did not routinely fail the CHAT at 18 months.<br>Committee on Infant Hearing of the American Speech–Language–Hearing Association developed guidelines for the audiologic assessment of children from birth through 36 months of age.36 They recommended that all children with developmental delays, particularly those with delays in social and language development, have a formal audiologic hearing evaluation. Three studies have documented that conductive, sensorineural, or mixed hearing loss can co-occur with autism, and that some children with autism may be incorrectly thought to have peripheral hearing loss.<br>The National Center for Environmental Health of the Centers for Disease Control and Prevention recommends that children with developmental delays, even without frank pica, should be screened for lead poisoning. | H1 | | | |
| 118 | Garzon, D. L., C. Thrasher, et al. (2010). "Providing optimal care for children with developmental disorders." Nurse Pract 35(10): 30-39; quiz 39-40. | 2010 | Review: General | | | p.c. | | touches on ID of children with ASD, family/cultural concerns; transition planning and care coordination; managing comorbidities | | | M1 | | |
| 119 | Al-Qabandi, M., J. W. Gorter, et al. (2011). "Early autism detection: are we ready for routine screening?" Pediatrics 128(1): e211-217 | 2011 | Review: Screening | | | p.c. | | | no autism screening programs have been studied in randomized controlled trials; early internsive behav. intervention, at best, produced modest results in selected subgroups; sensitivity/specificity of screening tools vary depending on age and symptom severity; M-CHAT promising but unable to recognize 15 of 100 children with autism; no strong evidence of effectiveness of therapies and availability limited (wait lists) and cost is prohibitive; on basis of available research-- not enough sound evidence to support implementation of routine population based screening for autism | H3 | | | |

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|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 120 | Barton, M. L., T. Dumont-Mathieu, et al. (2011). "Screening Young Children for Autism Spectrum Disorders in Primary Practice." J Autism Dev Disord. | 2011 | Review: Screening | <24 mos. | | p.c. | | Reviews early screening tools currently in use and offers recommendations for integrating autism specific screening into primary care | despite a limited data base regarding the psychometric properties of specific screeners, the value of screening far exceeds the risks;there is insufficient data to support using broadband developmental screeners in lieu of autism specific screeners. there is clear and disconcerting evidence of disparities in the early identification of children with ASDs based on racial and ethnic group membership and socioeconomic status; There are well-studied instruments which can provide quick and accurate screening in the context of ongoing developmental surveillance and thoughtful elicitation/ clarification of parental concerns. | H1 | | | |
| 121 | Johnson, C. P. and S. M. Myers (2007). "Identification and evaluation of children with autism spectrum disorders." Pediatrics **120**(5): 1183-1215. | 2007 | Review: General, with emphasis on screen | | | p.c. | | Addresses background information, incl. definition, hisotry, epidemiology, diagnositc crieteria, early signs, neuropathologic aspects, and etiologic possibilities in ASDs; provides algorithm to help pediatricians develop strategy for early ID of children w/ ASD | | H1 | | | |
| 122 | Matson, J. L. and M. Sipes (2010). "Methods of early diagnosis and tracking for autism and pervasive developmental disorder not otherwise specified (PDDNOS)." Journal of Developmental and Physical Disabilities **22**(4): 343-358. | 2010 | Review: Screening | | | p.c. | | review of 22 scales designed to diagnose autism that have been adopted for early ID and other scales designed specifically to diagnose children at age 18-36 | | H1 | | | |
| 123 | Myers, S. S., Johnson, C. P. (2007). "Management of Children with Autism Spectrum Disorders." Journal of American Academy of Pediatrics. | 2007 | Review-Treatment | young/older children and adolescents | | p.c. | | reviews educational strategies and associated therapies that are primary treatments for children with autism | There is a growing body of evidence that supports the efficacy of certain interventions in ameliorating symptoms and enhancing functioning, but much remains to be learned. In addition to their impor tant roles in identifying ASDs through screening and surveillance, establishing the diagnosis, conducting an etiologic evaluation, and providing genetic counseling after a diagnosis is made, pediatricians and other primary health care professionals are in a position to provide important longitudinal medical care and to support and educate families and guide them to empirically supported interventions for their children | H1 | | | |
| 124 | Nadel, S. and J. E. Poss (2007). "Early detection of autism spectrum disorders: screening between 12 and 24 months of age." J Am Acad Nurse Pract **19**(8): 408-417. | 2007 | Review: General-Screening | 12-24 mo. | | p.c. | | present NPs with info on screening for ASDs in children between 12-24 mo.; rec. provided for appropriate referrals and initiation of early intervention | | | M1 | | |
| 125 | Nelson, H. D., P. Nygren, et al. (2006). "Screening for speech and language delay in preschool children: systematic evidence review for the US Preventive Services Task Force." Pediatrics **117**(2): e298-319. | 2006 | Review: Screening | preschool | | p.c. | | evaluate strengths and limits of evidence about effectiveness of screenings and interventions for speech and language delay in pre-school aged children to determine balance of benefits and adverse effects of routine screening in primary care | | | M1 | | |

| # | Citation | Year | Type: Topic | Population/ Subpopulations | | Study Setting | Screening Tools/ Measures | Summary Notes | Results/Findings | Weighted Relevance | | | TEP Review |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 126 | Norris, M. and L. Lecavalier (2010). "Screening accuracy of Level 2 autism spectrum disorder rating scales. A review of selected instruments." Autism **14**(4): 263-284. | 2010 | Review: Screening (level 2) | > 3 years | | p.c. | | examine the state of Level 2 care giver completed rating scales for screening of ASDs in indv. above age of 3 years | Overall, the SCQ performed well, the SRS and ASSQ showed promise, and the GARS/GARS-2 and ASDS demonstrated poor sensitivity. This review indicates that Level 2 ASD caregiver-completed rating scales are in need of much more scientific scrutiny. | | M1 | | |
| 127 | Pierce, K., S. J. Glatt, et al. (2009). "The power and promise of identifying autism early: insights from the search for clinical and biological markers." Ann Clin Psychiatry **21**(3): 132-147. | 2009 | Review: Screening | > 12 mo. | | p.c. | | | literature on early ID of autism is discussed, incl. timescale for onset of social symptoms; new method for prospective study of autism called "1 Year Well-Baby Check-Up Approach"-allows for prospective study of the disorder in simplex families with infants as young as 12 mo of age | H1 | | | |
| 128 | Rapin, I. and R. F. Tuchman (2008). "Autism: definition, neurobiology, screening, diagnosis." Pediatr Clin North Am **55**(5): 1129-1146, viii. | 2008 | Review: General | | | p.c. | | Highlights definition, neurobiology, screeing and diagnosis of autism genetics, immunology, imaging, and neurophysiology reviewed with emphasis on areas that impact pediatricians | | H1 | | | |
| 129 | Robins, D. L. (2008). "Screening for autism spectrum disorders in primary care settings." Autism **12**(5): 537-556. | 2008 | Review: Screening | | | p.c. | Broad developmental instruments: Parents' Evaluation of Developmental Status and the Ages and Stages Questionnaires; autism-specific tools: CHAT & M-CHAT, PDD-ST, STAT | Level of screening=type of sample:Level I-defined as an unselected sample, Level II- selected children already ID-ed as being at risk for developmental disorder; Breadth of Sample=range of difficultues the screening tools attempts to identify: broad screening instruments-ID multiple range of developmental difficulties, disorder specific tools-focus on single disorder or class of disorders | The development of the M-CHAT, a Level I and Level II screening instrument, is described, and current research and clinical use of the M-CHAT are reviewed, including description of the structured follow-up interview which reduces the false-positive rate of the parent-report M-CHAT | H1 | | | |
| 130 | Soares, N. S. and D. R. Patel (2012). "Office screening and early identification of children with autism." Pediatr Clin North Am 59(1): 89-102, x-xi. | 2012 | Review: Screening | | | p.c. | | review DD & ASD screening tools, provides separate table of Red Flags for primary care providers | tempting to use single instrument for general development and autism screening in interests of time & simplicity but study found almost 3/4 of children who screened positive for an ASD using M-CHAT did not elicit developmental concerns on a GD measure such as the PEDS-->implies that a GD screen not sufficiently specific to replace/use as 1st stage screening tool for ASD; GD screening tools miss delays in domains of social & communication skills; study- even after child had positive screening for ASD, families waited an average 7 months to pursue diagnostic evaluation; obstacles to integrating existing GD screening tools into EHR: tools are copyrighted; exception= PEDS, which has an elec.version autism screening tool, only M-CHAT has an elec. version. many practices are using paper versions of the screening tools, then scan into EHRs-manual scoring - duplication of effort with scanning, making automated retrieval, tracking, and linkage to referral templates difficult; no highly validated tools for screening ASDs before the age of 15 months, so continuing developmental surveillance is essential, with particular scrutiny for red flags in high-risk pop.; screen at 18 months and again at 24-30 mos, because 25% of children may not be screened as positive early, due to “regressive” ASD. | H1 | | | |

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| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 131 | Weissman, L., L. Sices, et al. (2010). ""He is just a little shy like me": screening for autism in a young child." J Dev Behav Pediatr **31**(8): 675-677. | 2010 | Case Study | 22 mo. | | | | case study of 22 mo. Old boy | | | | L3 | |
| 132 | Wetherby, A. M., S. Brosnan-Maddox, et al. (2008). "Validation of the Infant-Toddler Checklist as a broadband screener for autism spectrum disorders from 9 to 24 months of age." Autism **12**(5): 487-511. | 2008 | Review/ Single Study: Screening | 9-24 mo. | | p.c. | | review of research on accuracy of screeners for children with ASD that have been administered to general pediatric samples; present results of population based study with a broadband screener to detect children with communication delays including children with ASD | | H2 | | | |
| 133 | Charman, T. and K. Gotham (2012). "Measurement Issues: Screening and diagnostic instruments for autism spectrum disorders - lessons from research and practise." Child and Adolescent Mental Health. | 2012 | Review: Screening | | | p.c. | | development of screening and diagnostic instruments for ASDs; reviews this progress, including recent innovations, focusing on those instruments for which the strongest research data on validity exists, and then addresses issues arising from their use in clinical settings | Less than a handful of population screening studies have been conducted; even fewer did long-term follow-up required to fully ascertain sensitivity; prospective screening studies have shown that it is possible to prospectively identify ASD, including in children about whom parents & professionals did not have preexisting concerns, from 18 months or earlier. Most common early signs captured by the screen are impairments or delays in early emerging social communication behaviours, such as response to name, joint attention and play behaviours, although sensory abnormalities or a restricted repertoire of play activities might also be early indicators of later ASD. However, these early signs are neither universal nor specific to ASD as opposed to other neurodevelopmental disorders one-stage screening has been shown to have low PPV so risk of overreferral. research suggests caution about recommending universal population screening; Need to both train providers in autism as well as introduce screening tools. ASD screening & dx instruments provide valuable sources of information about a child or young person, which can help clinicians make more informed judgements about onward referral and diagnosis. However, they do not 'do the job' for the clinical team in that no instrument score equates to a diagnosis. | H1 | | | |
| 134 | Fernandopulle, N. (2011). "Measurement of autism: a review of four screening measures." Indian J Psychol Med **33**(1): 5-10. | 2011 | Review: Screening | | | p.c. | Childhood Asperger Syndrome Test, Autism Behavior Checklist, Social Communication Questionnaire, Social Responsiveness Scale | reviewed with reference to their ability to discriminate the three major components of autism and measure across the whole spectrum of autism | none of the measures were able to effectively tap into and differentiate between all points on the spectrum | | M1 | | |
| 135 | Huerta, M. and C. Lord (2012). "Diagnostic evaluation of autism spectrum disorders." Pediatr Clin North Am 59(1): 103-111, xi. | 2012 | Review: Screening | | | p.c. | | research on ID and evaluation of ASDs is reviewed and best practices for clinical work discussed | Focuses on the complexities of dx ASD, particularly given the wide spectrum of possible symptom presentation and other possible DD. Good diagnostic evaluations of ASD include the use of instruments designed to assess multiple domains of functioning and behavior, the inclusion of parents and caregivers as active partners, and the consideration of developmental factors throughout the diagnostic process. | | M1 | | |

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| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 136 | Carr, J. E. and L. A. LeBlanc (2007). "Autism spectrum disorders in early childhood: an overview for practicing physicians." Prim Care 34(2): 343-359 | 2007 | Review-General-Treatment | < 3 yr | | p.c. | | includes screening/diagnosis but mostly about treatment | recommends phsyicians adopt universal screening practices and evaluate parental reports rather liberally; establish relationship with local diagnosticians can help expedite the diagnostic process for families; make recommendations/referrals for treatment informed by available empiric support; educate patients and families about comorbid medical problems | | M1 | | |
| 137 | Lindgren, S. (2008). "Evidence Based Interventions for Autism Spectrum Disorder." | 2008 | Review-General-Treatment | | | p.c. | | includes screening/diagnosis but mostly about treatment | early autism treatment:primary focus should be on the child's acquisition of communication, social, play, and academic skills; medication cannot cure but can help provide control over some symptoms | H1 | | | |
| 138 | Inglese, M. D. (2009). "Caring for children with autism spectrum disorder. Part II: screening, diagnosis, and management." J Pediatr Nurs 24(1): 49-59. | 2009 | Review: Screening | infants + toddlers < 3 years | | p.c. | | reviews screening and diagnosis; infants and toddlers development, and ASD; treatment and ongoing management | the Autism Behavior Checklist (ABC) has not been particularly helpful in screening or diagnosis, but it is helpful in tracking changes in a child already having an autism spectrum diagnosis. The ABC is thus also useful when monitoring treatment responses | | M1 | | |
| 139 | Zwaigenbaum, L. (2010). "Advances in the early detection of autism." Curr Opin Neurol 23(2): 97-102. | 2010 | Review: Screening | < 2 yr | | p.c. | | discusses previous and prospective studies for screening | Recent advances in early detection research have resulted from prospective studies of high-risk infants and large ASD screening studies conducted in community settings; exciting progress has been made in establishing the efficacy of ASD-specific interventions; increasing emphasis on opportunities to link early behavioral expression to the underlying neurobiology of ASD, potentially bringing us closer to the fundamental mechanisms underlying this disorder. | | M1 | | |
| 140 | Zwaigenbaum, L., S. Bryson, et al. (2009). "Clinical assessment and management of toddlers with suspected autism spectrum disorder: insights from studies of high-risk infants." Pediatrics 123(5): 1383-1391. | 2009 | Review: Screening | | | | | review of findings from recent studies on early development of children with ASD, summarizing current knowledge on early signs of ASD, screening properties of early detection tools, current best practice for ASD before age 2 | ID of concerns, should lead to further assessment of child's social, communication, play development in office, incl. parent's concerns and observations, hearing should also be assessed; if concerns remain, should be referred to early intervention services and further evaluation by professions | H1 | | | |
| 141 | NICE Clinical Guideline-Autism-Recognistion, referral, and diagnosis of children and young people on the autism spectrum (2011) | 2011 | Guideline: General | birth- 19 years old | | | | This guideline covers the recognition, referral and diagnosis of autism in children and young people from birth up to 19 years; signs and symptoms that should prompt professionals working with children, young people, and their parents or carers to consider autism; information requirements from other agencies; components of diagnostic assessment after referral; appropriate information and day-to-day support for children, young people and their parents or carers during referral, assessment and diagnosis; and ineffective diagnostic interventions and approaches. | | H1 | | | |

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| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| | **Biomarker/Genetics** | | | | | | | | | | | | |
| 142 | Bosl, W., A. Tierney, et al. (2011). "EEG complexity as a biomarker for autism spectrum disorder risk." BMC Med 9: 18. | 2011 | Single Study | each age group from 6-24 mo. | typical vs. high risk (siblings w ASD) | p.c. | EEG | looking at typically developing children vs. group of infants at high risk for ASD (defined by basis of older sibling with ASD) classification computed seperately within each age group from 6-24 mo. | | | | | |
| 143 | Cai, G., L. Edelmann, et al. (2008). "Multiplex ligation---dependent probe amplification for genetic screening in autism spectrum disorders: efficient identification of known microduplications and identification of a novel microduplication in ASMT." BMC Med Genomics 1: 50. | 2008 | Single Study | | unrelated subjects ascertained for ASDs | p.c. | using MLPA to screen microdeletions and microduplications | | two subjects with typical AS-associated interstital duplications of 15q11-q13 PWA region of maternal origin; t additional subjects showed smalled duplications of PWA region-incl. GABRB3 and ATP10A in one case, MKRN3, MAGEL2, and NDN in other; two subjects showed duplication of 22q11/DiGeorge syndrome region; one carried 12kb deletion; 2 showed partial duplicaton of TM4SF2 gene | | | | |
| 144 | Gandal, M. J., J. C. Edgar, et al. (2010). "Validating gamma oscillations and delayed auditory responses as translational biomarkers of autism." Biol Psychiatry 68(12): 1100---1106. | 2010 | Single Study | mean 10.20 | | p.c. | abnormal neural dynamics of ASDs | whole cortex magnetoencephalography recored in the children during auditory pre-tone presentation- superior temporal gyrus activity was analyzed in time and freq. domains; auditory evoked potentional were recorded in mice prenatally exposed to alproic acid and analyzed with analagous methods | VPA-exposed mice demonstrated selective behav. alterations related to autism (reduced social interactions, repetitive self-grooming, etc.); autistic subjects and VPA exposed mice showed similar latency delay | | | | |
| 145 | Kantojarvi, K., I. Kotala, et al. (2011). "Fine mapping of Xq11.1---q21.33 and mutation screening of RPS6KA6, ZNF711, ACSL4, DLG3, and IL1RAPL2 for autism spectrum disorders (ASD)." Autism Res 4(3): 228---233. | 2011 | Single Study | | ASD, X-linked MR | p.c. | common genetic background for ASDs and X-linked MR/used 26 microsatellite markers and linkage analysis in 99 Finnish families with ASD | | total of 6 novel and 11 known single nuceotide polymorphisms were identified | | | | |
| 146 | Kern, J. K., D. A. Geier, et al. (2011). "Toxicity biomarkers in autism spectrum disorder: a blinded study of urinary porphyrins." Pediatr Int 53(2): 147---153. | 2011 | Single Study | 2-13 yr | ASD | p.c. | increased levels associated with mercury toxicity/urinary porphyrin biomarkers compared | ASD had significantly increased levels of 5cxP, prcP, and cP in comparison to controls- no significant difference in non-Hg assoc. urinary porphyrins; influence of other factors (genetics and other metals) cannot be completely ruled out | | | | | |

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| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 147 | Tsiaras, V., P. G. Simos, et al. (2011). "Extracting biomarkers of autism from MEG resting---state functional connectivity networks." Comput Biol Med 41(12): 1166---1177. | 2011 | Single Study | mean 18.8 yr | | p.c. | distinct features of resting-state functional networks: non linear measure of generalized synchronization (robust interdependence measure [RIM]), mutual information(MI), and partial directed coherence (PDC) | | | | | | |
| 148 | Wang, L., M. T. Angley, et al. (2011). "A review of candidate urinary biomarkers for autism spectrum disorder." Biomarkers 16(7): 537---552. | 2010 | Review | | | p.c. | abnormal urniary creatine (CR) abd guanidinoacetate (GAA) levels | | | | | | |
| 149 | Croen, L. A., P. Goines, et al. (2008). "Brain-derived neurotrophic factor and autism: maternal and infant peripheral blood levels in the Early Markers for Autism (EMA) Study." Autism Res 1(2): 130-137. | 2008 | Single Study | 7-8 year | | p.c. | levels of BDNF | investigate levels of brain-derived neurotrophic factor (BDNF) in mid-pregnancy and neonatal blood specimens as early biologic markers for autism; BDNF measured in archived mid pregnancy and neonatal blood specimens using highly sensitive bead-based assay | concentration of BDNF in maternal mid-pregnancy and neonatal specimens was similar across all three study groups | | | | |
| 150 | Gray, K. M., J. Taffe, et al. (2012). "Could head circumference be used to screen for autism in young males with developmental delay?" J Paediatr Child Health 48(4): 329-334. | 2012 | Single Study | | developmental delay with autism vs. developmental delay without autism | p.c. | head circumference | examine head circumference at birth and head circumference growth rates in young children with autism and developmental delay and young children with developmental delay without autism | no differences were found between group of children with autism and developmental delay compared with group with developmental delay only; when compared with range of celected normative medians- children with autism found to have significantly smaller head circumferences at birth and larger head circumference at 18.5 mo. of age | | | | |
| 151 | Ray, B., J. M. Long, et al. (2011). "Increased secreted amyloid precursor protein-alpha (sAPPalpha) in severe autism: proposal of a specific, anabolic pathway and putative biomarker." PLoS One 6(6): e20405. | 2011 | Single Study | | | p.c. | sAPPalpha, sAPPbeta, Abeta peptides; BDNF | | sAPPalpha levels are increased and BDNF levels decreased in plasma of patients with severe autism; Abeta1-40, Abeta1-42, and sAPPbeta levels are significantly decreased in plasma of patients with severe autism | | | | |
| 152 | Roberts, T. P., S. Y. Khan, et al. (2010). "MEG detection of delayed auditory evoked responses in autism spectrum disorders: towards an imaging biomarker for autism." Autism Res 3(1): 8-18. | 2010 | Single Study | | | p.c. | STG M50; M100 STG activity | subjects presented tones with frequencies of 200, 300, 500, and 1,000 Hz, and left and right STG M50 and M100 STG activity was examined | examining right hemisphere 500 Hz condition had largest latency differences--sensitivity 75%, specificity 81% | | | | |

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| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 153 | Wang, L., M. T. Angley, et al. (2009). "Is urinary indolyl-3-acryloylglycine a biomarker for autism with gastrointestinal symptoms?" Biomarkers 14(8): 596-603. | 2009 | Single Study | | | p.c. | Indolyl-3-acryloylglycine (IAG) | | urinary IAG levels in morning urine samples were statistically significantly higher in children with ASD whose caregivers reported presence of chronic gastrointestinal disturbance than children with ASD without GI disturbance; urinary IAG was not significantly higher in children with ASD, compared with siblings or unrelated controls without ASD | | | | |
| 154 | McGrew, S. G., B. R. Peters, et al. (2011). "Diagnostic Yield of Chromosomal Microarray Analysis in an Autism Primary Care Practice: Which Guidelines to Implement?" J Autism Dev Disord. | 2011 | Single Study | | | p.c. | Chromosomal Microarray Analysis (CMA)-G banded karyotype, Fragile X DNA testing | testing in a primary pediatrics autism practice | found 20 patients with abnormal CMA/3 abnormal karyotype/1 fragile X syndrome; no relationship between CMA result and cognitive level, seizures, dysmorphology, congenital malformations, or behavior | | | | |
| 155 | Bruno, D. L., Z. Stark, et al. (2011). "Extending the scope of diagnostic chromosome analysis: detection of single gene defects using high-resolution SNP microarrays." Hum Mutat 32(12): 1500-1506. | 2011 | Single Study | | | p.c. | high resolution SNP microarrays | describe 14 examples of single gene disorders cause by intragenic changes from a consecutive set of 6500 tests using high resolution SNP microarrays | 9 of cases confrimed clinical diagnosis [followed a phenotype to genotype approach] 5 diagnosed by the lab analysis in absence of a specific clinical diagnosis [followed a genotype to phenotype approach | | | | |
| 156 | Kaminsky, E. B., V. Kaul, et al. (2011). "An evidence-based approach to establish the functional and clinical significance of copy number variants in intellectual and developmental disabilities." Genet Med 13(9): 777-784. | 2011 | Single Study | | | p.c. | copy number variants | consortium of diagnostic lab was estb to share copy nmber variant and phenotypic data in a central, public database; focused on recurrent deletions and duplications involving 14 copy number variant regions | compared with controls, 14 deletions and 7 duplications were significantly overrepresented in cases- providing a clinical diagnosis as pathogenic | | | | |
| 157 | Coulter, M. E., D. T. Miller, et al. (2011). "Chromosomal microarray testing influences medical management." Genet Med 13(9): 770-776. | 2011 | Single Study | | | p.c. | chromosomal microarray testing | conducted a retrospective chart review of CMA testing performed during 12 mo period on patients with developmental delay, intellectual disability, ASD and congenital anomalies | 13.1% had clinically relevant results, either abnormal or variants of possible significance (VPS)- abnormal variants generated higher rate of recommendations for clinical action compared to VPS | | | | |
| 158 | Shen, Y., K. A. Dies, et al. (2010). "Clinical genetic testing for patients with autism spectrum disorders." Pediatrics 125(4): e727-735. | 2010 | Single Study | | | p.c. | G-banded karyotype, fragile X DNA testing, CMA | | karyotype yielded abnormal results in 19 of 852 patients; fragile X testing abnormal in 4 of 861; CMA identified deletions/duplications in 154/848 patients | | | | |
| 159 | Roesser, J. (2011). "Diagnostic yield of genetic testing in children diagnosed with autism spectrum disorders at a regional referral center." Clin Pediatr (Phila) 50(9): 834-843. | 2011 | Single Study | | | p.c. | Chromosomal Microarray Analysis (CMA), karyotype, Fragile X DNA testing | systematically review genetic testing guidelines in the evaluation of children with ASDs; medical records were abstracted for genetic testing and factors associated with this testing | abnormalities were found on karyotype in 2.3% and in DNA for fragile X in 0.04%; concludes diagnostic yield of genetic testing was low in this population | | | | |

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| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 160 | Bradstreet, J. J., S. Smith, et al. (2010). "Biomarker-guided interventions of clinically relevant conditions associated with autism spectrum disorders and attention deficit hyperactivity disorder." Altern Med Rev 15(1): 15-32. | 2010 | Review | | | p.c. | oxidative stress, methylation capacity and transsulfuration, immune function, gastrointestinal problems, and toxic metal burden | | | | | | |
| 161 | Frustaci, A., M. Neri, et al. (2012). "Oxidative stress-related biomarkers in autism: Systematic review and meta-analyses." Free Radic Biol Med. | 2012 | Review | | | p.c. | oxidative stress related blood biomarkers | Lit review on relationship btwn. oxidative damage and ASDs | | | | | |
| 162 | Ratajczak, H. V. (2011). "Theoretical aspects of autism: biomarkers--a review." J Immunotoxicol 8(1): 80-94. | 2011 | Review | | | p.c. | gastrointestinal, immunologic, neurologic, and toxicologic systems of the body | presents approach toward development of an objective measure of autism; summarizes evidence of hormones, metabolites, amino acids and other biomarkers | | | | | |
| 163 | Veenstra-VanderWeele, J. and R. D. Blakely (2012). "Networking in autism: leveraging genetic, biomarker and model system findings in the search for new treatments." Neuropsychopharmacology 37(1): 196-212. | 2012 | Review | | | p.c. | mammalian target of rapamycin (mTOR)-linked synaptic plasticity mechanism; postnatal rescue of brain and behavioral phenotypes; elevated seratonin (5-HT) levels and surge in brain growth in first 2 years of life | review of diversity of ASD phenotypesand its genetic origins and biomarkers; discuss opportunities for translation of these findings into novel ASD treatments, focusing on mTor and 5-HT signaling pathways and possible intersection; anticipate progress in models systems using bona fide ASD associated molecular changes that have potential to accelerate the development of ASD dianostics and therapeutics | | | | | |
| 164 | Blatt, G. J. and S. H. Fatemi (2011). "Alterations in GABAergic biomarkers in the autism brain: research findings and clinical implications." Anat Rec (Hoboken) 294(10): 1646-1652. | 2011 | Review | | | p.c. | The key synthesizing enzymes for GABA,). GABA receptor density, number, and protein expression are all decreased in the cerebellum and in select cortical areas | the neurochemical profile of affected individuals, revealed in postmortem tissue studies, is only recently emerging. One major component that appears highly impacted in autism is the GABAergic system | | | | | |

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| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 165 | Toriello, H. V. (2012). "Approach to the genetic evaluation of the child with autism." Pediatr Clin North Am 59(1): 113-128, xi. | 2012 | Review | | | p.c. | | looking at studies that attempt to identify specific genes involved in predisposition to autis (subdivided into metabolic, mitochondrial, chromosomal, monogenic); examines what conditions should be considered in child who does not appear to have syndromic cause as reason for autistic phenotype | | | | | |
| 166 | Kearney, H. M., S. T. South, et al. (2011). "American College of Medical Genetics recommendations for the design and performance expectations for clinical genomic copy number microarrays intended for use in the postnatal setting for detection of constitutional abnormalities." Genet Med 13(7): 676-679. | 2011 | Review | | | p.c. | genomic copy number microarrays | suggests microarray platforms be evauated and manufacturers regulated for the ability to accurately measure copy number gains or losses in DNA (analytical validation) and that subsequent interpretation of findings and assignment of clinical significance be determined by medical professionals with appropriate training and certification | | | | | |
| 167 | Griffin, R. and C. Westbury (2011). "Infant EEG activity as a biomarker for autism: a promising approach or a false promise?" BMC Med **9**: 61. | 2011 | Review | | | p.c. | | review of Bosl et al. claim that measure of EEG complexity can be used to detect infants at high risk for Autism; conflation between "high risk" as a population level property and "high risk" as property of an indv.; examine results with respect to baseline prevalence rates- neccessary to distinguish infants with a biological risk of autism from typically developing infants with sibling with autism | | | | | |
| | **Other Co-morbidities & Testing for Medical Conditions/ Differential Diagnosis** | | | | | | | | | | | | |
| 168 | Kuban, K. C., T. M. O'Shea, et al. (2009). "Positive screening on the Modified Checklist for Autism in Toddlers (M-CHAT) in extremely low gestational age newborns." J Pediatr **154**(4): 535-540 e531. | 2009 | Single Study | | | p.c. | Modified Checklist for Autism in Toddlers (M-CHAT) | test hypothesis that children born preterm are more likely to screen positive on M-CHAT | major motor, cogn., visual, hearing impairments apprear to account for more than half of positive M-CHAT screens in extremely low gestational age newborns; even after such impairments were eliminated-10% (nearly double the expected rate) screened positive | | M2 | | |
| 169 | DiGuiseppi, C., S. Hepburn, et al. (2010). "Screening for autism spectrum disorders in children with Down syndrome: population prevalence and screening test characteristics." J Dev Behav Pediatr **31**(3): 181-191. | 2010 | Single Study | mean age 73.4 mo. (range 31-142) | | p.c. | modified checklist for autism in toddlers or social communication questionnaire, as appropriate | assessed prevalence of ASD and screening test characteristics in Down syndrome | prevalance of ASD among children with Down syndrome aged 2-11 years is substantially higher than in the general population; modified checklist and social comm questionnaire highly sensitive in children with Down syndrome but could result in many false positives | | M2 | | |

| # | Citation | Year | Type: Topic | Population/ Subpopulations | | Study Setting | Screening Tools/ Measures | Summary Notes | Results/Findings | Weighted Relevance | | | TEP Review |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 170 | Limperopoulos, C., H. Bassan, et al. (2008). "Positive screening for autism in ex-preterm infants: prevalence and risk factors." Pediatrics **121**(4): 758-765. | 2008 | Single Study | ex-preterm infants or =1500g at birth/ follow-up 21.9 mo. | | p.c. | MRI, demographic, prenatal, interpartum, acute post-natal, and short term outcome data; M-CHAT, Vineland Adaptive Behavior Schale, Child Behavior Checklist | underwent conventional MRI studies at preterm and/or term adjusted age; collected pertinent demographic, prenatal, interpartum, acute post-natal, and short term outcome data; followup done at mean age of 21.9 mo. using M-CHAT, Vineland Adaptive, CBC | 26% of ex-preterm infants had positive result on autism screening tool; early autistic behaviors seem to be underrecognized feature of very low birth rate infants | H2 | | | |
| 171 | Luyster, R. J., K. C. Kuban, et al. (2011). "The Modified Checklist for Autism in Toddlers in extremely low gestational age newborns: individual items associated with motor, cognitive, vision and hearing limitations." Paediatr Perinat Epidemiol **25**(4): 366-376. | 2011 | Single Study | 24 mo. | | p.c. | Neurological assessment, Bayley Scales of Infant Development, Second Edition, Modified Checklist in Autism for Toddlers, medical history form | detailed examination of M-CHAT items in large sample of children born at extremely low gestational age | M-CHAT items failed more freq. by children with concurrently identified impairments; frequency of item failure increased with severity of impairments | H2 | | | |
| 172 | Moore, T., S. Johnson, et al. (2012). "Screening for autism in extremely preterm infants: problems in interpretation." Dev Med Child Neurol **54**(6): 514-520. | 2012 | Single Study | recruited those born not more than 26 weeks' gestational age; questionnaire distr.at 2 years of age | | p.c. | Modified Checklist for Autism in Toddlers (M-CHAT) | report prevalence of, risk factors for positive autism screens used in M-CHAT for children born extremely pre-term in England | prevalence of positive M-CHAT screens in this population was 41%; coexisting disabilities was present in 62%; prevalence of positive M-CHAT screens in extremely preterm children is high esp. in children with neurodevelopmental impairment | H2 | | | |
| 173 | Ventola, P., J. Kleinman, et al. (2007). "Differentiating between autism spectrum disorders and other developmental disabilities in children who failed a screening instrument for ASD." J Autism Dev Disord **37**(3): 425-436. | 2007 | Single Study | | | p.c. | Autistic Diagnostic Observation Schedule; Generic (ADOS); Childhood Autism Rating Scale (CARS), Modified Checklist for Autism in Toddlers (M-CHAT) | compares behavioral presentation of toddlers with ASD and global developmental delay (DD) or developmental language disorder (DLD) | to date, 195 children have failed the M-CHAT and have been diagnosed with ASD DD or DLD; children with ASD had prominent and consistent impairments in socialization skills, more impaired in some aspects of communication, play, and sensory processing; children with ASD and children with DD/DLD shared common features but certain behavioral markers differentiated the two groups | H2 | | | |

| # | Citation | Year | Type: Topic | Population/ Subpopulations | | Study Setting | Screening Tools/ Measures | Summary Notes | Results/Findings | Weighted Relevance | | | TEP Review |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 174 | Verte, S., H. M. Geurts, et al. (2006). "Can the Children's Communication Checklist differentiate autism spectrum subtypes?" Autism **10**(3): 266-287. | 2006 | Single Study | 6-13 years | | p.c. | Children's Communication Checklist (CCC); Autism Diagnostic Interview-Revised | explores whether children with high functioning autism (HFA) Asperger syndrome (AS), and PDD-NOS can be differentiated on CCC | little differences were found- HFA cluster showed most autism characteristics, followed by combined HFA+AS, then PDD-NOS cluster | | M2 | | |
| 175 | Matson, J. L., S. Mahan, et al. (2011). "Effects of symptoms of co-morbid psychopathology on challenging behaviours among infants and toddlers with Autistic Disorder and PDD-NOS as assessed with the Baby and Infant Screen for Children with aUtIsm Traits (BISCUIT)." Dev Neurorehabil **14**(3): 129-139. | 2011 | Single Study | | | p.c. | BISCUIT-Part 2;BISCUIT-Part 3 | examine whether level of symptoms of co-morbid psychopathology exacerbated challenging behaviors in young children with ASD | participants scoring high on symptoms of Avoidance and Tantrum/Conduct problems, inattention/impulsivity, eat/sleep concerns had greater rates of aggressive, self-injurious behaviors and stereotypies; | | M2 | | |
| 176 | van Tongerloo, M. A., H. H. Bor, et al. (2011). "Detecting Autism Spectrum Disorders in the General Practitioner'S Practice." J Autism Dev Disord. | 2011 | Single Study: Screening | mean age 8.74 (boys); 9.17 (girls) | ASD | p.c. | | looking at comorbidities | visited GP's surgery more often with anxiety disorders, enuresis, and sleeping disorders; referred more often to physiotherapists and speech terapists and had tympanostomy tubres and tonsil-lectomies more often; depression in parents of children with ASD was remarkably prevalent | H2 | | | |
| 177 | Tyler, C.V., Schramm, S. et al. (2010) Electronic Health Record Analysis of the Care of Adults with Intellectural and Other developmental Disabilities. Journal of Policy and Practice in Intellectual Disabilities 7(3) pp 204–210 | 2010 | Review: HER/comorbidities | mean 39 | | p.c. | | | IDD were significantly more likely to carry comorbid diagnoses of epilepsy, constipation, osteoporosis, obesity, and hyperlipidemia, but were significantly less likely to bear comorbid diagnoses of hypertension, diabetes, osteoarthritis, heart failure, coronary heart disease, and chronic obstructive pulmonary disease. Despite a lower mean body mass index, individuals with IDD were more likely to be labeled obese. Only genetic consultation rates were higher in the IDD cohort. Health services research related to persons with IDD is becoming more feasible as large health systems adopt EHRs | | M1 | | |
| 178 | Tyler, C.V., Schramm, S.C., et al. (2011) "Chronic disease risks in young adults with autism spectrum disorder: forewarned is forearmed."Am J Intellect Dev Disabil. 116(5):371-80. | 2011 | Review: EHR/comorbidities | | | p.c. | | | Without intervention, adults with autism spectrum disorder appear to be at significant risk for developing diabetes, coronary heart disease, and cancer by midlife. | H1 | | | |
| | **Electronic Health Records/Autism** | | | | | | | | | | | | |
| 179 | Oberleitner, R., et al. (2005). "Health informatics: a roadmap for autism knowledge sharing." Stud Health Technol Inform. 114:321-6. | 2005 | Review: EHR | | | p.c. | | outlines recommended principles and approaches for utilizing state-of-the-art information systems technology and population-based registries to facilitate collection, analysis, and reporting of autism patient data | | | M3 | | |
| 180 | Guevara, J., Butler, A., Grundmeier, R. (2010) "Implementing Developmental Screening in Urban Practices Using the EHR" <http://www.nichq.org/pdf/2010_Presentations/A2%20Guevara_James%20ppt.pdf> | 2010 | PPT-EHR | | | p.c. | | ppt presentation goals: review current recommendations for developmental screening; understand common barriers to screening and ID strategies to address these barriers; learn how to utilize the HER to facilitate developmental screening | | H3 | | | |

| # | Citation | Year | Type: Topic | Population/ Subpopulations | | Study Setting | Screening Tools/ Measures | Summary Notes | Results/Findings | Weighted Relevance | | | TEP Review |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Age Range | Patient Type | | | | | High | Med | Low | H/M/L |
| 181 | Jensen, R.E., Chan, K.S, et al. (2009). Implementing Electronic Health Record-Based Quality Measures for Developmental Screening. Pediatrics 2009;124;e648 | 2009 | Single Study: EHR | | | p.c. | | discuss the role of EHRs in measuring the quality of child developmental services; shows how these systems can be used to monitor developmental screening and highlights the potential of EHR systems to adapt, to modify, and to create new data elements. EHR systems of all 6 health care organizations could implement measures examining developmental screening rates and could ID/track children with abnormal screening results; most systems did not have the ability to capture data for more-complex EHR-based measures. | organizations have developed sophisticated EHR systems that can facilitate quality measurement and developmental screening. Two of the 3 measures developed could be implemented with few or no modifications to existing systems-emphasizes the flexibility and potential of these systems; strong evidence that the implementation of EHR-based measures for developmental screening is feasible; biggest challenges is the inability to identify screenings and abnormal findings consistently across eligible patient encounters. This is largely attributable to the inconsistent use of procedure and billing codes within and across patient records. Alternatively, settling on a common developmental screening instrument might encourage greater consistency. Another challenge was that no organization was able to track medical specialist follow-up care adequately. This is consistent with the general difficulty EHR systems have in tracking a provider's actions | H2 | | | |

## Summary Comments: Autism Domain

- This scan focused on screening for autism utilizing both broadband developmental delay screeners and autism-specific screeners, as well as whether autism-specific screening should be universal or follow a positive screen on a broadband tool. The scan also covers studies/reviews of individual screeners and their psychometric properties. Additional searches were conducted to extract literature pertaining to the use of electronic health records with respect to autism as well as literature exploring biomarkers and genetic factors.

Universal Screening with Autism Specific Tools

- There is a lack of consensus in the literature regarding recommendation for universal screening using autism-specific measures. Professional societies differ with respect to type of guidelines endorsed: e.g., AAP endorses universal ASD-specific screening at 18- & 24-months; American Academy of Neurology and the Child Neurology Society endorses ASD-screening for those who fail routine developmental surveillance
- Those against universal ASD screening cite: lack of gold standard tool that has acceptable sensitivity, specificity, and positive predictive value; possible costs/harms of false positives and over-referrals; over-reliance on observational studies in drawing conclusions regarding screening and treatment effectiveness; studies demonstrating "only modest" intervention effectiveness for certain subgroups; overall lack of research rigor in the field; primary care providers are short-pressed for time and often do not do even basic DD screening; access to care may be problematic as health care system may not be able to handle dramatic increases in potential ASD referrals
- Those in favor of universal ASD screening cite research that demonstrates: screening tools can identify ASD in kids as early as 18 months or less, starting treatment earlier is associated with improved outcomes, several interventions are associated with improved outcomes for most children, parents would rather know earlier re: potential autism diagnosis even if false positive rather than potentially miss an early diagnosis; children who test false positive for ASD are often diagnosed with other DD; universal ASD screening has potential to reduce disparities in identification of ASD across different racial/ethnic and SES groups
    - "the consensus appears to be that despite a limited data base regarding the psychometric properties of specific screeners, the value of screening far exceeds the risk" (Barton et al., 2012)
- Very few studies have examined the sequence of screening→referral→ treatment, and it does not appear that there have been any significant RCTs pertaining to autism screening
- Based on SORT criteria, Carbone et al. 2010: I. treating co-morbid medical & psychiatric conditions improves functioning for children with autism = A (consistent, good quality evidence); II. EIBI can improve autism outcomes = B (inconsistent/limited quality evidence); III. autism-specific screening tool should be administered at all 18- & 24-month visits = C (consensus, disease-oriented evidence, usual practice, expert opinion, case series)
- There seems to be more consensus in favor of universal broadband DD screening, but this was only researched for the lit scan in connection with autism so it is based on more limited information
- Studies suggest that broadband DD screeners and ASD screeners do not identify the same populations and that DD screeners may miss patients with ASD; need for more research to determine how effective broadband screeners are in identifying ASD

- "there is insufficient data to support using broadband developmental screeners in lieu of autism specific screeners" (Barton et al., 2012)

Autism-Specific Screening Tools

- No gold standard autism-specific screening tool: need more adequate info about fewer screeners vs. current state of research where there's inadequate info on many screeners.
- Generally, tools that combine parental survey report along with either provider observation and/or a short parent follow-up interview are more effective
- Some studies suggest standardized screener more effective than clinician judgment alone
- General agreement that if using ASD screening tools, repeat screenings over time are necessary
- Performance of the instrument must be judged against the purpose, setting, population
- Promising tools primary care: M-CHAT, Autism Screening Questionnaire
- Measures for tracking changes/monitoring outcomes in children diagnosed with Autism: Autism Behavior Checklist (ABC) and ATEC

Integrating Screening into Practice

- Provider surveys of current practice generally reveal that one-third or fewer providers use standardized DD screeners and even fewer standardized ASD screeners
- Studies of implementing ASD screening into practice demonstrate that the screening intervention is generally well-received by primary care providers and can be consistently administered
- Need to train providers; not enough to just implement tools
- General recommendations include audiology evaluations and lead testing for those screening ASD-positive

Electronic Health Record & ASD Practices

- See Jensen et al. 2009 summary next page
- Issues of using copyrighted tools in EHR; many still relying on paper-based then entering into EHR (duplication of effort)

## EHR & Quality Measures for Developmental Screening (Jensen et al. 2009)

**Measure 1: Screening Occurrence:**
Proportion of children who have had a standardized, validated developmental screening assessment at their 9-, 18-, or 30-month well-child visits within the past 12 months
Numerator: Number of children with a completed developmental screening
Denominator: Number of children who had a 9- (8–10) month, 18- (15–24) month, or 30- (30–40) month well-child visit within the past 12 months

**Measure 2: Abnormal Screening Result**
Proportion of children with an abnormal screening result (as defined by the cut-off specified by the screening tool used) documented on their problem list within the past 12 months
Numerator: Number of children with documentation of an abnormal screening result on their problem list
Denominator: Number of children with an abnormal screening result at a well-child visit within the past 12 months

**Measure 3: Specialist Follow-up**
Proportion of children seen by a specialist (for consultation or referral) for developmental concerns within the past 12 months who had their specialist note reviewed by their primary clinician
Numerator: Number of children with documentation of primary clinician review of a post-specialist visit consultation note
Denominator: Number of children with an abnormal screening result who were referred to and seen by a specialist within the past 12 months

This study of early-adopting health care organizations shows that these organizations have developed sophisticated EHR systems that can facilitate quality measurement and developmental screening. Two of the 3 measures developed could be implemented with few or no modifications to existing systems, which emphasizes the flexibility and potential of these systems. The organizations also exhibited considerable variation in what data they captured and how they stored data, indicating that the information needed for quality indicators can be successfully generated by a variety of EHR systems. This is strong evidence that the implementation of EHR-based measures for developmental screening is feasible. An important next step is to establish uniform measurement specifications for each screening indicator. One of the biggest challenges is the inability to identify screenings and abnormal findings consistently across eligible patient encounters. This is largely attributable to the inconsistent use of procedure and billing codes within and across patient records. Alternatively, settling on a common developmental screening instrument might encourage greater consistency. Another challenge was that no organization was able to track medical specialist follow-up care adequately. This is consistent with the general difficulty EHR systems have in tracking a provider's actions.

# Acronyms

| | |
|---|---|
| **AHRQ** | Agency for Healthcare Research and Quality |
| **ASPE** | Assistant Secretary for Planning and Evaluation |
| **BH** | Behavioral Health |
| **BHeM** | Behavioral Health eMeasures |
| **CDC** | Centers for Disease Control and Prevention |
| **CEO** | Chief Executive Officer |
| **CQAIMH** | Center for Quality Assessment and Improvement in Mental Health |
| **CQM** | Clinical Quality Measure |
| **CMS** | Centers for Medicare and Medicaid Services |
| **FACP** | Fellow, American College of Physicians |
| **FASAM** | Fellow, American Society of Addiction Medicine |
| **EDC** | Education Development Center |
| **EHR** | Electronic Health Record |
| **HITECH** | Health Information Technology for Economic and Clinical Health Act of 2009 |
| **HITPC** | Health Information Technology Policy Committee |
| **HRSA** | Health Resources and Services Administration |
| **IHS** | Indian Health Service |
| **ICSI** | Institute for Clinical Systems Improvement |
| **IT** | Information Technology |
| **MD** | Medical Doctor |
| **MPH** | Masters in Public Health |
| **MSW** | Masters in Social Work |
| **NIAAA** | National Institute on Alcohol Abuse and Alcoholism |
| **NICHD** | National Institute of Child Health and Health Development |
| **NIDA** | National Institute on Drug Abuse |
| **NIH** | National Institutes of Health |
| **NIMH** | National Institute of Mental Health |
| **NINR** | National Institute of Nursing Research |

| | |
|---|---|
| **NIST** | National Institute of Standards and Technology |
| **NCBDDD** | National Center on Birth Defects and Developmental Disabilities |
| **NORC** | National Organization for Research at the University of Chicago |
| **NQMC** | National Quality Measures Clearinghouse |
| **NPRM** | Notice of Proposed Rulemaking |
| **NQF** | National Quality Forum |
| **ONC** | Office of the National Coordinator for Health Information Technology |
| **ONDIEH** | Office of Noncommunicable Disease, Injury and Environmental Health |
| **PhD** | Doctorate of Philosophy |
| **PHQ** | Patient Health Questionnaire |
| **PRO** | Patient Recorded Outcome |
| **PROMIS** | Patient Reported Outcomes Measurement Information System |
| **PsyD** | Doctor of Psychology |
| **SAMHSA** | Substance Abuse and Mental Health Services Administration |
| **RHI** | Resolution Health, Inc. |
| **ScD** | Doctor of Science |
| **TEP** | Technical Evaluation Panel |
| **TJC** | The Joint Commission |
| **US** | United States of America |
| **VA** | Department of Veterans Affairs |
| **VHA** | Veterans Health Administration |
| **VP** | Vice President |