SCREENING FOR AUTISM AT 12 MONTHS: PHYSICIAN AND PARENT REACTIONS

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Disclosure Statement

- Four members of our research team are authors of the nonpublished First Year Inventory (Baranek, Watson, Crais, & Reznick, 2003), which will be discussed in relation to other screening tools during today’s presentation. We do not, however, have any financial interest in the tool, as it is currently used as part of our research protocol in our studies.

Background

- Early identification of children at-risk for ASD has become a critical national health care issue.
- Recent reports estimate an ASD diagnosis for every 1 in 91 children (Kogan, 2009).
- Early intervention significantly improves developmental outcomes for young children with ASD (Kasari, Paparella, Freeman, & Jahromi, 2008; Dawson et al., 2010).
- Access to services contingent on accurate diagnosis.

How Early Is Diagnosis?

- Diagnosis of children with ASD typically occurs around 3-4+ years of age (older in minority populations and lower SES).
- Diagnosis is rare before two years of age.
- Access to diagnosis is contingent on accurate early screening and referral.
- What barriers exist to early screening and referral?

Screening For ASD

- No blood, medical, genetic, neurological tests for screening for ASD.
- ASD is screened by observing & recording behaviors (certain criteria reached).
- Surveillance by professionals.
- Parent report of concerns.
- Standardized screening tools.
- What guidelines are available for screening?

Screening Guidelines

- The American Academy of Pediatrics Guidelines recommend:
  - General developmental screening at 9-, 18- and 30- months (AAP, 2006).
  - ASD-specific screenings at 18- and 24-months (Johnson & Myers, 2007).
- Adoption of guidelines has been slow. The use of developmental screening tools in current practice is reported to be between 50 - 75% (Band, Silverstein, Glacoe, Gupta & Tonniges, 2005; Sices, Feudtner, McLaughlin, Drotar & Williams, 2004).
Why Screen for ASD in Infants & Toddlers?

- Symptoms are recognized in majority of kids by 18 months
- 25-30%: regression reported, usually between 18 & 24 months
- AAP (2007): Screen ALL children twice by 24 months (specifically at 18 & 24 months)
- AAP does not endorse a specific screener

CSBS-DP Infant-Toddler Checklist

- Parent-report tool
- 25 questions across communication & play domains
- Empirically supported for 9-24 month olds (Wetherby & Prizant, 2004) and shown to raise red flags for autism although is not an autism specific screener

Level I Autism Screening Tools

- Modified Checklist for Autism in Toddlers (M-CHAT: Robins, Fein, Barton, & Green, 2001)

- Currently the best evidence available is for the M-CHAT as ASD-specific screener for 18 and 24 months, but only if used with the follow-up questions (Kleinman et al., 2008; Robins, 2008)

Level I Screening Tools

- Distinguish infants and toddlers with autism from the general population
- General Developmental Screening
  - Ages and Stages Questionnaire (ASQ) (Squires, Bricker, & Potter, 1997)
  - Child Development Inventories (CDI) (Ireton, 1992)

Why ASD-Specific Screening?

- General developmental screening tools may not tap the same domains
  - e.g. 6/38 children screened positive by PEDS also screened positive on M-CHAT
  - 16/114 children screened negative by PEDS screened positive by M-CHAT (Pinto-Martin et al., 2008)

Modified Checklist for Autism (MCHAT) (23 questions: Yes/No format)

1. Does your child enjoy being swung, bounced on your knee, etc?
2. Does your child take an interest in other children?
3. Does your child like climbing on things, such as up stairs?
4. Does your child enjoy playing peek-a-boo/hide-and-seek?
5. Does your child ever pretend, for example, to talk on the phone or take care of a doll or other pretend things?
6. Does your child ever use his/her index finger to point, to ask for something?
MCHAT Follow-up Interview Questions

1. “You reported that ___________ does not enjoy being swung, bounced on your knee, etc. Is this still true?”
   If no, then ask again, “Then s/he does like to be bounced or swung?”
   If yes, PASS

   If yes, “When you swing or bounce him/her, how does s/he react?”
   Laughs or smiles? Yes No
   Talks or babbles? Yes No

   Requests more by holding out her/his arms? Yes No
   If Yes, PASS If no, FAIL

Background of First Year Inventory

- Based on retrospective video analysis, clear behavioral markers for ASD at 12 months of age are evident (Baranek, 1999, Reznick et al., 2006)
- Most children seen by primary care physicians at 12 months for vaccinations
- From retrospective work, UNC-CH research team developed parent report tool to identify risk for ASD in 12 month olds - First Year Inventory (Baranek, Watson, Crais, & Reznick, 2003)

First Year Inventory (FYI, Baranek, Watson, Crais, & Reznick, 2003)

- Social-communication & sensory-regulatory items
- 63 items total
- 46 items: parents check “never,” “seldom,” “sometimes,” or “often”
- 14 multiple choice items
- 1 item on sound production
- 2 open-ended questions regarding concerns & unusual physical or medical characteristics

FYI Sample Questions: Checklist & Multiple-choice

- Does your baby turn to look at you when you call your baby’s name?
- Does your baby seem overly sensitive to your touch?

When you introduce your baby to a new game (peek-a-boo, so-big, patty-cake, etc.), how does your baby respond?
- a) Almost always joins in immediately without any help
- b) Usually joins in, with a little help
- c) Joins in only with a lot of help
- d) Doesn’t seem very interested in new baby games

What do you typically have to do to get your baby to look up from playing with a favorite toy?
- a) Just show him or her a different toy
- b) Move, shake or make a noise with the different toy
- c) Take the favorite toy away and give your baby the different toy

Identification of Autism & Other DD

- Using cut-off for both Social-Communication & Sensory-Regulatory domains yielded best performance of FYI in screening for ASD:
  - Positive Predictive Value = 31 (31% chance child identified by FYI will have ASD at age 3)
  - Only 2 of 13 children identified by the FYI had no diagnosis of a DD AND no parental concerns at 3 years
  - Sensitivity = 44 (44% of children with ASD by age 3 were identified by FYI)

Cautions re: Interpreting Screening Results in Toddlers

- Failed screening indicates need for further evaluation
- Even with the best current practice, about 50% of children who fail screening with M-CHAT will not be diagnosed with an ASD
- True sensitivity and specificity for M-CHAT (and other screeners recommended in US) are unknown; requires knowledge of “missed cases” among children who screen negative
- Sensitivity estimated at 77-92 (with follow-up questions)
- Thus, professionals using Level 1 ASD screens should be VERY CAREFUL about making definitive statements to parents
Clinical Use of FYI?

- Not ready yet!
- Only normed for children at exactly 12 months of age
- Too long
- Scoring is complicated
- Keep up with our progress on our website: http://www.med.unc.edu/ahs/pearls
- That leads us to our focus group study

Purpose of Current Study

- Ongoing research is needed to improve the clinical usefulness of the FYI
- Little is known about current practices in ASD screening at 12 months
- Current study employed focus group methodology to better understand:
  - screening practices in primary care in central North Carolina
  - the concerns of parents at 12-month well-child visits in central NC
- Findings will be utilized to inform a revision of the FYI

Methodology

- Eight provider focus groups and 3 parent focus groups were conducted between November 2009 and May 2010
- Two sets of focus group questions were developed in an iterative process by the research team over a period of 6 weeks (Krueger, 2009)
- Focus group questions targeted differing concerns of providers and parents
  - Provider questions specific to use of screening tool at 12-months
  - Parent questions focused on concerns and experiences during 12-month well-child visits (including developmental & ASD screening practices)

Focus Group Questions: PROVIDERS

- “Think back...” What are some of the issues that you feel are important to consider when screening for ASD in young children?
- What specifically would you be looking for in a screening tool for 12-month olds?
- What would enable you/your practice to use a screening tool like this (if developed)?
- What are the challenges to using a screening tool like this (if developed)?

Focus Group Questions: PARENTS

Think back to your child’s recent 12-month well-child visit. What happened at that visit?

- Did your child have any type of screening of his/her development at the 12-month visit, and if so, was it helpful?
- What if your child was screened and the screening was wrong and your child didn’t have a problem, how would you feel? And what about if your child wasn’t screened and later developed a problem, how would you feel then?

Focus Group Questions: PARENTS (continued)

- How important do you think it is to screen for ASD early?
- What if your physician told you there was a new parent questionnaire to use at the 12 month well-child checkup to look for early signs of ASD? Would you want to complete the form and have your child screened, why or why not? (15 minutes)
- If your doctor’s office didn’t offer screenings of this type, do you have any ideas about where else you might go, who you might talk to, or where you might look to get information about your young child’s development?
**PROVIDERS: Settings & Participants**

- Primary care practices were identified within a 60-mile radius of Chapel Hill and recruited by phone, fax, or email.
- 8 one-hour focus groups were held between November 2009 and May 2010.

<table>
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<tr>
<th>Provider Focus Groups</th>
<th>MD</th>
<th>PA</th>
<th>Nurse</th>
<th>Resident</th>
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<td>Total</td>
<td>22</td>
<td>2</td>
<td>35</td>
<td>1</td>
<td>1</td>
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**PARENTS: Settings & Participants**

- 3 two-hour focus groups were held between November 2009 and May 2010.
- Letters were sent to 200 parents of children whose birth dates fell between January 2009 and March 2009.

<table>
<thead>
<tr>
<th>Parent Focus Groups</th>
<th>n = 22 (4M, 17F)</th>
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<tbody>
<tr>
<td>Age</td>
<td>71% 31-40 years, 19% 26-30 years, 5% 18-25 years, 5% 41-50 years</td>
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<tr>
<td>Education</td>
<td>65% 4-year college degree or higher, 14% HS/Some college</td>
</tr>
<tr>
<td>Race</td>
<td>67% White, 14% Black, 9% Asian, 10% Multi-ethnic</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>81% Non-Hispanic/Latino, 9% Hispanic/Latino, 10% Unknown</td>
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**Data Analysis**

- A grounded theory approach was utilized in this analysis (Strauss & Corbin, 1990).
- Team members trained on use of Atlas Ti Qualitative Data Analysis Software.
- Through an inductive, exploratory process, team members came to consensus on 5 open codes and 30 axial codes.
- The interrelated nature of the codes became evident during coding.
- Conceptual framework began to take shape.

**Focus Group Findings PROVIDERS & PARENTS**

- **Conceptual Framework**
  - **Coding Scheme**
    - **Context**
      - Culture/SES
      - Early Intervention System & Resources
      - Hispanic context
      - Insurance billing
      - Medicaid system
    - **Procedural**
      - Current Practice
      - Desired Practice
      - How administered
      - Training
      - How administered
    - **Ethical Moral Dilemmas**
      - Intercultural
        - Need for clear evidence
      - Interpersonal
        - How do you know ASD when you see it?
        - Need for clear evidence
      - Intra office procedures and communication
      - Parent concerns about procedures
      - How/where parents seek information

- **Interpersonal**
  - How do you know ASD when you see it?
  - Need for clear evidence

- **Tool Design**
  - **Cost**
  - **Format**
  - **Length**
  - **Literacy Level**
  - **Social validity**
  - **Wording of items**
**Interpersonal: How Do You Know It?**

**PROVIDER:**
"… even today I had a patient who had some delays and no one could answer for me what I would be looking for if I needed to refer her on further for some issues, which was kind of frustrating for me…or whether or not we should screen her for autism…and she's FOUR (years old)"

**Interpersonal: Need for Clear Evidence**

**PROVIDERS:**
"I want to see data that it works. If it’s not a useful... screening tool, I’m not going to spend the time."

"I think it’s important but I would be concerned about how accurate it is at 18 months for autism."

**PARENTS:**
"I would want to know, but I would have a lot of questions about defining at-risk, like, does this mean he definitely has a problem? Or can I fix the problem? But, so it would make me nervous, obviously that would not be ideal…"

"I wouldn’t screen my daughter; if there was an autism screen I wouldn’t use it. I think it’s such a very powerful label, and it puts a child on such a very specific trajectory, for the rest of their…until they get to school, even after they get to school…that… I…think there would have to be a very severe and very obvious diagnosis of autism…before I would allow my daughter to be screened for that."
**Focus Group Findings: PROVIDERS**

**Context: El System and Resources**

"Another thing is sort of belief that the system is really going to GET these kids, cause it’s one thing for us to screen at 12 months old, but if the system is overwhelmed, and we have all public patients so it’s ALL going to the same few agencies, you know is there CAPACITY…. and what…are they really going to be plugged into what is deemed the ideal INTERVENTION at that age for kids with autism. Or are they just going to get…you know once a week developmental…you know I mean if it’s something that NOT the gold standard of therapy to REALLY influence them at that age, then I think what’s the point?"

**Context: Insurance billing**

"Pretty much assuming that in this day and time that reimbursement is ALWAYS a problem. Even if it was covered last week it’s probably not covered THIS week. So, I’m sorry, there’s a little sarcasm in my voice about coverage for this, but the system is so FRACTURED it’s hard to know what’s going to get covered."

**Context: Culture/SES**

"…it just depends on the level of education of the parent and how sophisticated they are. Some of my parents don’t read very well, so some of the questions on there are difficult for them. And then some of my patients are Spanish speaking so it’s not appropriate…"

"The odds that one of OUR kids…if we see a 12 month old and we diagnose him….that he’s gonna get that kind of intensive, effective, wonderful, timely, age appropriate, language appropriate services is almost zero. So, you know…it’s demotivating."

**Ethical Moral Dilemmas**
Ethical Moral Dilemmas

“I think one of the things for me is just apprehension as to how the family is going to respond when I mention a term like autism that has such a stigma.”

“Well I think you just have to think about the risks, there’s risks that come with screening. You have to weigh the benefits and the risks and there’s definite harms and that can happen.”

Study Summary

- Methodology allowed for detailed look at perceptions of primary care providers & parents
- Host of factors to consider regarding screening (e.g., interpersonal, contextual)
- Some confusion in understanding between screening & diagnosis (even with providers)
- Range of opinions across providers and across parents (so a “one size screening process” does not fit all)
- Perceptions of primary care providers and parents are essential in the screening process
- Where do SLPS fit into the screening process?

Preparation of SLPs for Participating In Early Screening For ASD

- Develop knowledge of symptoms of ASD
- Appropriate background education & training in screening
- Learn about community resources
- ASHA Guidelines for SLPS on Autism
  - http://www.asha.org/slp/clinical/autismresources.html
  - www.asha.org/policy
- Reach out to other healthcare providers in your community (e.g., primary care providers such as pediatricians, family physicians; early care and education professionals)

Supplements to Screening: Enhancing Professional Observations

- Use milestone charts (resources at end)
- Consider behaviors at different ages drawn from research findings
- What kinds of behaviors to look for that indicate risk of ASD?
- Looking for both absence of behaviors and presence of some behaviors

Typical Development of Social & Communication Milestones

Milestones which are lacking in some 2-3 year olds with ASD seen in typically developing child by 15 – 18 months

- 3-6 months: emergence of turn taking (vocal, play)
- 6-9 months: response to name
- 9-12 months: follow attention of others; social referencing with novel stimuli; good & varied communication
- 12-15 months: initiate joint attention; beginning verbal communication; functional play
- 15-18 months: early pretend play; developing vocabulary of words used in different situations

Key Features of ASD

Impairments in
(a) social interaction,
(b) communication, and
(c) restricted range of interests and/or repetitive or stereotyped behaviors, interests, and activities
How Early Can We Recognize ASD? At Age 24 months?

Social Symptoms:
- Lack of responsiveness
- Abnormal eye contact
- Lack of facial expressions
- Limited shared enjoyment
- Limited interest in peek-a-boo/social games
- Poor imitation
- Poor peer relationships/limited interest in other children

Communication Symptoms:
- Delayed speech/speech problems
- Loss of acquired words
- Doesn’t attract attention to own activities
- May not want parents to read/look at books together
- No showing, giving, or pointing to objects to share interest

How Early Can We Recognize ASD? At Age 24 Months?

Unusual activities & interests:
- Unusual play or attachment to objects
- Over or under reaction to sensory stimuli
- Irregular sleep-arousal rhythms
- Unusual visual interests (lights, fans)

How Early Can We Recognize ASD? At 18 Months?

Joint attention diminished, often absent
- Failure to share interest with others (e.g., monitor gaze of others; show or give objects, look at books together)
- Little or no pointing to show objects/events
- Pointing to get things may be present (regulate)
- Lack of sharing joy (except in tickle, roughhouse games)

(Baird et al., 2000; Cassell et al., 2007; Landa et al., 2007; Robins et al., 2001; Wetherby et al., 2004)

How Early Can We Recognize ASD? At 9-12 Months?

- Simple pretend play not emerging
- Failure to respond to name
- Lack of appropriate gaze
- Unusual prosody (rhythm of speech awkward)
- Repetitive movements/posturing

(Baird et al., 2000; Cassell et al., 2007; Landa et al., 2007; Robins et al., 2001; Wetherby et al., 2004)
How Early Can We Recognize ASD? At 9-12 months?

- Sensory-Motor/Sensory-Regulatory
  - More mouthing
  - More social touch aversions
  - Less visual orientation to novel stimuli
  - Difficulty shifting attention to new stimuli
  - Tendency to fixate attention instead of actively explore
  - Fewer goal directed behaviors & limited variety
  - Extreme passivity with extreme distress reactions

(Baranek, 1999; Cassell et al., 2007; Watson et al., 2008; Zwaigenbaum et al., 2006)

Effective Outreach to Primary Care in Your Community

- Providers, parents and the early childhood community must work together to improve screening and referral practices

- Resource: Tracking, Referral and Assessment Center for Excellence (TRACE) at the Orelana Hawks Puckett Institute
  [http://www.tracecenter.info](http://www.tracecenter.info)

Outreach to Primary Care in Your Community: Getting Started

- PLANNING
  - Identify the referral sources in your community
  - Prepare information about the benefits of referral to EI services (agencies, service coordination & contact info)

- IMPLEMENTATION
  - Visit the practice
  - Share information about your services
  - Consider partnerships (e.g., identify what common screening tools and assessments are being used)

Outreach to Primary Care in Your Community: Maintaining Contact

- FOLLOW-UP
  - Acknowledge all referrals
  - Keep the primary referral sources informed
  - Provide timely, personal feedback
  - Schedule follow-up visits

It Takes a Village: Who Else Has a Role? EARLY CHILDHOOD PROFESSIONALS

- ECE professionals often share that their biggest challenge is having to talk to parents about the possibility that a child might have a DD or ASD
- Often the ECE provider may be the first person to notice that a child is not meeting developmental milestones or is acting in an unusual way when compared to peers
Supporting ECE Professionals

- Autism Speaks has an excellent resource called “Talking to Parents About Autism”
- You can access the 15 min video via YouTube by searching for the title or at [www.autismspeaks.org/whatisit/talking_to_parents_action_kit.php#top](http://www.autismspeaks.org/whatisit/talking_to_parents_action_kit.php#top)
- Website includes an “action kit” with handouts for ECEP providers to talk with parents about developmental screening

If a ECE Professional Shares a Concern

You Can Encourage Her/Him to:
- Take notice
- Trust instincts
- Prepare to act
- Take focus off speech and language, put focus on social skills and interactions with peers


Take Notice

Share with ECE professionals that, while it’s not their job to diagnose ASD, it is helpful for them to get familiar with red flags such as:
- Loss of language or social skills
- Child not participating in or enjoying pretend play
- Child not playing with peers

Trust Instincts

Encourage ECE professionals to document their observations of behaviors that seem out of the ordinary. It’s helpful to take notes to show the parents.

Prepare to Act

- Noticing warning signs of DD or ASD is an indication that provider needs to talk with the family
- Remind them that they are familiar with the child, closely observed behavior; use as a focal point when talking to parents
- Consider cultural sensitivities

Next Steps

- Invite caregivers to observe the child in the childcare setting
- Ask if they have talked with child’s PCP and if he or she has noticed any concerns
- Recommend a developmental screening
- Be aware of local resources and share information about early intervention or referrals for screening or evaluation
- Maintain ongoing communication
Final Thoughts

- Improved Screening & Referral of children at risk for ASD is up to all of us!

We Are The Village!

Discussion & Questions

- What are some of the issues you are facing with screening and referral in your communities?
- What can you take away with you today?

Resources

- American Academy of Pediatrics
- CDC Learn the Signs/Act Early
  [www.cdc.gov/ncbddd/actearly/concerned.html](http://www.cdc.gov/ncbddd/actearly/concerned.html)
- Autism Speaks ASD glossary
  [http://www.autismspeaks.org/](http://www.autismspeaks.org/)
- MCHAT
  [http://www2.gsu.edu/~psydlr/Diana_L_Robins_Ph.D.html](http://www2.gsu.edu/~psydlr/Diana_L_Robins_Ph.D.html)
- Caring for Children with ASD: A Resource Toolkit for Clinicians
  [www.aap.org](http://www.aap.org)
- 9-12 months: Is Your One-Year Old Communicating with You? (AAP, 2004), [http://www.aap.org](http://www.aap.org)

References


Acknowledgements

- Current project conducted by the PEARLS team and supported by the Ireland Family Foundation
- Special thanks to Paul Mihas at the Odum Institute for his ongoing consultation

Resources

- [http://firstwords.fsu.edu](http://firstwords.fsu.edu) (Infant/Toddler Checklist & Scoring, ASD glossary)
- Pearls.med.unc.edu (our website for articles, presentations)
- National Professional Development Center on Autism Spectrum Disorders (24 evidence-based practices, training modules, online course)
- [http://www.asha.org/slp/clinical/autismresources.htm](http://www.asha.org/slp/clinical/autismresources.htm)
- [http://www.asha.org/policy](http://www.asha.org/policy)