Early Diagnosis of Autism Spectrum Disorder and the MCHAT-R/F

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Birth through Three Program
Objectives

• Identifying the importance of early screening and its benefits

• Discussing relevant research that support the identification of early signs of autism

• Applying the M-CHAT-R/F in your practice and identify the next steps for referral and further action.

• Learn how the MCHAT-R/F is used in the NM FIT program
Why should I care about early identification?

- Increase in prevalence
- Costs
- Early intervention
Prevalence Rates

Autism Prevalence Since 2000

1975: 1:5000
1985: 1:2500
1995: 1:500

1 in 166
1 in 150
1 in 125
1 in 110
1 in 88
1 in 68

CDC Prevalence Statistics for ASD
Diagnostic Trends

• ASD occurs worldwide in all ethnic and societal groups

• Median age of diagnosis in the United States is 4 (CDC ADDM, 2014)
  • Autism age 4 years
  • PDD-NOS age 4.2 years
  • Asperger’s 6.2 years

• Children from disadvantaged groups (i.e., lower SES, rural areas, ethnic minorities) demonstrate increased health disparities
  • Under-diagnosis or late diagnosis
  • Delay in intervention or lack of treatment options
Why do we need to get better at early identification?

• Economic Impact
  • Cost of autism in a lifetime averages between 1.4 million to 2.4 million
  • Economic burden for 2015 is $268.3 billion and estimated to be $460.8 billion in 2025 (Leigh & Du, 2015)

• Family Impact
  • Cost of medical and nonmedical care
  • Parents high level of stress
  • Loss of income/productivity
Early Identification to Improve Developmental Outcomes

• Early identification $\rightarrow$ early intervention
• Fully understanding a child’s presentation $\rightarrow$ the right kind of early intervention
• The right kind of early intervention $\rightarrow$ the best possible outcomes and reduce impact of ASD

Website for Part C
Information:
http://idea.ed.gov/part-c
Early Intervention Matters!

- Communication Skills
- Cognitive Functions
- Interpersonal Skills
- Motor Skills
- Responsibility
- School Placement
- Play Skills

- Autism Symptoms
- Problem Behaviors

National Autism Project, 2009
National Professional Development Center on Autism, 2009, 2010
Developmental Trajectories

• Changing the developmental trajectories of young children with ASD
The Central Issue

We want to ensure that all children have the best possible outcome in life.

How do we as providers do our part to make that happen?
How can we improve?

• Begin to identify ASD as early as we can

• Parents report concerns much earlier than the diagnosis occurs (IAN, 2010)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Avg. Age Initial Concern</th>
<th>Age of Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>1.7</td>
<td>3.2</td>
</tr>
<tr>
<td>AS</td>
<td>2.6</td>
<td>7.2</td>
</tr>
<tr>
<td>PDD-NOS</td>
<td>1.6</td>
<td>3.7</td>
</tr>
</tbody>
</table>

• Infants who later develop ASD begin to show signs in the first year of life, but begin to differentiate in the second year of life.
Developmental Screening AND Monitoring

• There is no time for the “Wait and See” approach to developmental concerns

• There is no harm done in screening and referral

• Early identification is key to access to intervention

• 2004 Learn the Signs Act Early campaign by the CDC

www.cdc.gov/actearly
• **Screening alone is insufficient**
  
  • 1 in 5 children with a disability will not be identified through a single developmental screening

• American Academy of Pediatrics (AAP) recommends that infants receive 7 well-child visits, during which ongoing **screening and monitoring** can occur and increase detection of disabilities

• AAP recommends specific screening for ASD **twice before two** (18 and 24 months)
Developmental Screening AND Monitoring

• Recent Research in 6 states
  • 60% pediatricians screened for ASD at 18 months
  • 50% pediatricians screened at 24 months (Arunyanart, et al., 2012)

• Screening in conjunction with clinical judgement
  • Brief observation screening study suggested that 39% of cases of ASD were missed by EXPERTS (Gabrielson, et al., 2015)
What are we looking for in children at risk for ASD?

- Qualitative delay/differences in social communication and behavior
  - Social attention and responsiveness
  - Joint attention
  - Gestures
  - Play
  - Shared enjoyment
  - Sensory
Important Considerations

• Cultural factors
  • Culture bound concepts
  • Screening tools may not “catch” certain behaviors
  • Reassess
  • Find a common ground

• Quality vs. Quantity

• Context

• Typical development vs. global developmental delays vs. ASD
Current Research

• Prospective Studies
  • Tracking infants
  • More rigorous research methods
  • Technologically advanced methods

• Example: Studying infant siblings of individuals with ASD
  • Baby Sibs Research Consortium
• **Recurrence risk:**
  - One in five later-born siblings of a child with ASD will receive a similar diagnosis.
  - If the child has more than one sibling with ASD, the risk of a similar diagnosis increases to one in three. (Ozonoff et al., 2011)

• **Of the later-born siblings who do not meet diagnosis, one in five show** (Messinger et al., 2013):
  - Higher levels of ASD symptoms based on ADOS-2.
  - Lower levels of developmental functioning (e.g., language, cognition, fine-motor development)
For a group of later-born siblings of children with ASD, a clinical diagnosis of ASD or Not ASD was made at 18, 24, and 36 months of age (Ozonoff, et al., 2015)

What was the stability of an ASD diagnosis at 36 months?

- 18 months was 93%
- 24 months was 82%
- There were relatively few children diagnosed with ASD at 18 or 24 months whose diagnosis was not confirmed at 36 months.
However, many children with ASD outcomes at 36 months had not yet been diagnosed at
  • 18 months (63%)
  • 24 months (41%)

Conclusions
  • Stability of ASD diagnosis was high at 18 and 24 months.
  • But, many children who were monitored were not diagnosed until 36 months.
  • We need to track development over time.
• **Longitudinal follow-up is critical** for children with early signs of social-communication difficulties, even if they do not meet diagnostic criteria at initial assessment.

• **A public health implication** is that screening for ASD may need to be repeated multiple times in the first years of life.

• In some children, there is a **period of early development in which ASD features unfold and emerge but have not yet reached levels supportive of a diagnosis**.
Using the MCHAT-R/F in Your Practice

- What is a screening tool?
- How to administer and score the MCHAT-R/F
- Next steps after scoring
What is a Screening Tool?

• Brief measure designed to identify children who are at-risk for atypical development

• SENSITIVE, not Specific:
  • Designed to “screen in” all possible cases.
  • This means a high false positive rate.
  • DOES NOT diagnose
Administering the MCHAT-R/F

• Identifies children aged **16 to 30 months** who should receive a diagnostic evaluation for possible ASD

• Translated into multiple languages

• A two-stage questionnaire:
  • First stage: 20 Yes/No Questions
  • Items 2, 5, and 12: “Yes” indicates ASD risk
  • All other items: “No” indicates ASD risk
  • Second stage: Follow up questions for items indicating ASD risk
### MCHAT-R/F

**M-CHAT-R™**

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

1. If you point at something across the room, does your child look at it?  
   
   (For example, if you point at a toy or an animal, does your child look at the toy or animal?)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

2. Have you ever wondered if your child might be deaf?

<table>
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<th>Yes</th>
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</table>

3. Does your child play pretend or make-believe?  
   (For example, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?)

<table>
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<tr>
<th>Yes</th>
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</tr>
</thead>
</table>

4. Does your child like climbing on things?  
   (For example, furniture, playground equipment, or stairs)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

5. Does your child make unusual finger movements near his or her eyes?  
   (For example, does your child wiggle his or her fingers close to his or her eyes?)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
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</table>

6. Does your child point with one finger to ask for something or to get help?  
   (For example, pointing to a snack or toy that is out of reach)

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</table>

7. Does your child point with one finger to show you something interesting?  
   (For example, pointing to an airplane in the sky or a big truck in the road)

<table>
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Scoring the MCHAT-R/F

• Add up the total number of At-risk responses

• This total is the Score

• Scores fall into three categories of risk
MCHAT-R/F

SCORING

Low-Risk
Medium-Risk
High-Risk
MCHAT-R/F

SCORING

Low-Risk

Score 0-2

if child is <24 months, screen again after second birthday

No further action unless surveillance indicates risk
MCHAT-R/F

SCORING

Medium-Risk

Total Score is 3-7

Administer the Follow-Up
MCHAT-R/F

M-CHAT-R™

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

1. If you point at something across the room, does your child look at it?  
   (FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?)

2. Have you ever wondered if your child might be deaf?  

3. Does your child play pretend or make-believe? (FOR EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?)

4. Does your child like climbing on things? (FOR EXAMPLE, furniture, playground equipment, or stairs)

5. Does your child make unusual finger movements near his or her eyes?  
   (FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?)

6. Does your child point with one finger to ask for something or to get help?  
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7. Does your child point with one finger to show you something interesting?  
   (FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road)
MCHAT-R/F

3. Does _______ play pretend or make-believe

Yes

Please give me an example of his/her pretend play. (If parent does not give a PASS example below, ask each individually.)

No

Does he/she ever...

Present to drink from a toy cup?

Pretend to eat from a toy spoon or fork?

Pretend to talk on the telephone?

Pretend to feed a doll or stuffed animal with real or imaginary food?

Push a car as if it is going along a pretend road?

Pretend to be a robot, an airplane, a ballerina, or any other favorite character?

Put a toy pot on a pretend stove?
MCHAT-R/F

SCORING

Medium-Risk
Total Score is 3-7

If score remains at 2 or higher, child screened positive. **Action required**: refer child for diagnostic evaluation and eligibility evaluation for early intervention.

If score on Follow-Up is 0-1, child has screened negative. No further action required unless surveillance indicates risk for ASD. Child should be rescreened at future well-child visits.
MCHAT-R/F

SCORING

High-Risk
Total Score is 8-20

It is acceptable to bypass the Follow-Up and refer immediately for diagnostic evaluation and eligibility evaluation for early intervention.
MCHAT-R/F Next Steps

**Low Risk**

Screen again after 2\textsuperscript{nd} birthday. No further action is needed unless risk is identified.

**Medium Risk**

Score on follow up is 2 or higher: ACTION REQUIRED. Refer for diagnostic evaluation and early intervention.

Score on follow up is 0-1: No further action is needed. Child should be re-screened at future well child visits.

**High Risk**

ACTION REQUIRED: It is acceptable to bypass follow-up stage and refer immediately for diagnostic evaluation and early intervention.
Where Can I Find the MCHAT-R/F

http://mchatscreen.com/
Paper version

https://m-chat.org/
Online version
New Mexico Family Infant Toddler (FIT) Program

• In any given year FIT Serves between 12,000 to 15,000 families

• We provide screening, developmental evaluation, and if eligible a variety of services such as Speech, Occupational Therapy, and Physical Therapy
FIT and the MCHAT-R/F

• FIT Program added M-Chat R/F into standards July 2015

• Conduct an autism screening utilizing the M-CHAT-R/F for children in the FIT Program.
  • For children referred between 18 months and 30 months of age the M-CHAT-R/F autism screening shall be conducted and as part of their Comprehensive Multidisciplinary Evaluation (CME).
  • For children referred who are younger than 18 months the M-CHAT-R/F autism screening shall be conducted once the child is 18 months old and again at 24 months of age
    • Personnel may bill for the time spent conducting the screening based on the location where the screening takes place
FIT and the MCHAT-R/F

• If a child shows a need for further evaluation then FIT will refer to the ECEP Program at UNM or help family with outside referral at their request

• The goal is to help children get identified early and have appropriate services in place

• We want to support families through every step of the process
Thank you.

Questions?