Screening and Referral
In a Coordinated System of Care

LEARNING OBJECTIVES

• Understand the landscape in Colorado around efforts to increase screening and referral
• Learn the policy recommendations for standardized developmental screening
• Discuss the definition of “Coordinated System of Care as it relates to screening for developmental delay
• Understand how this relates to Medical Home
• What are the roles and opportunities for public health teams in screening and referral

ABCD Vision and Mission

Vision: Colorado’s children reach maximum developmental potential

Mission: To encourage the use of standardized developmental screening tool in health care settings across Colorado
to facilitate early identification and referral

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Colorado-Lay of the Land

• Colorado has 919 pediatric and family practices
• 70% of pediatric practices have implemented standardized developmental screening for children birth to five
• 27% of all practices in Colorado have implemented standardized developmental screening for children birth to five
• Recent provider survey indicates that 90% of practices that use a standardized developmental screening tool, use it at a minimum 3x3
• 76% of practices that implemented a SDST refer to Early Intervention Colorado
• From November 1, 2008 to October 31, 2011, physician referrals have increased by 64%
• ABCD team members are actively working with community partners in 38 out of 64 counties

Colorado-Lay of the Land

• Recent national survey of AAP members, 1620 responses (55% response rate), ½ of respondents reported using standardized screening tools (doubled between 2002 and 2009)
• CO rate based on 2007 National Survey of Children’s Health (asked parents on phone interview) 25.6% (national ave 19.5% with range of 10.7 to 47%) (Bethell C. et al)
• There are many screening efforts going on
• Lack of coordination has a negative impact
• It is critical for communities to develop a coordinated system of care
## AAP policy on screening for Potential Developmental Delay and Autism

- Administer a standardized developmental screening tool to every child at 9, 18 and 24/30 months of age.
- Administer an autism specific standardized screening tool to every child at 18 and 24/30 months of age.
- Perform surveillance for potential developmental delay and autism at every well child visit.

## AAP Guidelines

- Focus of AAP Guidelines was to catch children early and refer to Early Intervention.
- Panel of experts.
- Reviewed all of the available evidence.
- Came up with the particular ages because of what was happening developmentally at those ages.

## Why Screen?

- Developmental disabilities are the most common disorders among children and adults rivaling only asthma and obesity (Newacheck PW, et al and Rosenberg SA, et al).
- 16-18% of all children aged 0-18 have a developmental disability. Approximately 12% of school aged children receive special educational services.
- Healthy People 2010 identifies developmental disabilities as one of the 6 most important health concerns in the United States.
- Children with developmental delays are entitled to services through the state (IDEA).

**Why Screen**

- We screen for conditions or diseases that we may not catch if not for screening.
  - Asymptomatic in early phases.
- We screen for conditions or diseases that if caught early may be able to reverse or have better outcomes.
- We screen when there are guidelines.
Why Screen?

- Developmental delay and ASD can be subtle and difficult to detect
- There may not be symptoms of early delay
- Early Intervention can make a huge difference
- Guidelines exist to recommend screening:
  - AAP recommends:
    - Surveillance at every well-child care (WCC)
    - Standardized developmental screening tool at 9, 18, 30 months
    - Administer an autism-specific standardized screening tool to every child at 18 and 24/30 months of age


What Makes a Good Screening Tool?

- High Sensitivity
  - Able to pick out people with condition from the general population
  - Pick up condition early in course when something can be done
  - Low false negative results
- High Specificity
  - Low false positive results
- Simple to administer
- Low Cost
- Safe
- Acceptable to patients and clinicians


Examples of Good Screening Tools

- Ages and Stages Questionnaire (ASQ)
- PEDS (Parent Evaluation of Developmental Status)
- Modified Checklist for Autism in Toddlers (MCAT)

ASQ: Screening for Developmental Delay

- Parent or Caregiver completed screening tool
- Series of questionnaires for children ages 1 month to 5.5 years
- Tool to accurately identify children at risk for developmental delay
- Sensitivity is 70%
- Specificity is 90%
- Domains Screened
  - Communication
  - Fine Motor
  - Gross Motor
  - Problem Solving
  - Personal Social
ASQ-SE: Screening for Social Emotional Concerns

- Parent or Caregiver completed screening tool
- Series of questionnaires for children ages 3 months to 5.5 years
- The ASQ:SE was developed to complement the ASQ by providing information specifically addressing the social and emotional behavior of children ranging from age 3 – 66 months.
- The ASQ:SE focuses on a child’s social and emotional behavior and therefore should be used in conjunction with the ASQ or another developmental screening measure that provides information on a child’s communicative, motor, problem-solving and adaptive behaviors.
- Screening groups of young children for social or emotional problems without also examining their cognitive, communicative, and motor behavior will likely yield, at best, an incomplete, and at worst, an inaccurate picture of the children’s behavioral repertoires. Again, the ASQ:SE should be used in conjunction with developmental screening tools that provide information on general child functioning in communication, motor and cognitive areas.
- Prior to initiating screening for Social Emotional delays the community referral algorithm must be defined.

MCHAT: Screening for Autism

- Most common tool for toddlers is the M-CHAT (modified checklist for autism in toddlers) which is good for ages 16-30 months.
- For children over 4 yrs the SCQ (Social Communication Questionnaire) can be used but remember there is no recommendation for universal screening at this age.

What do with concerning scores on an ASQ

- 0-3 years refer to Early Intervention Colorado
  [www.eicolorado.org](http://www.eicolorado.org)
- 3-5 years refer to Child Find
- Consider referral for a developmental evaluation if there is concern about a specific medical diagnosis
- Share results with child’s healthcare provider

What do with concerning scores on a MCHAT

- Refer for a developmental/ASD evaluation
- Refer to Early Intervention Colorado (age 0-3) or to Child Find (age 3 and over)
- Refer for Audiology evaluation (even if newborn hearing screen was normal)
- Share results with child’s healthcare provider
Other reasons to refer for ASD evaluation

- If anyone (parent, teacher, caregiver, provider, etc) has a concern you still refer even if the MCHAT was normal
- If a child has an older sibling with ASD consider referral for evaluation very early

What is a Coordinated System of Care

- Comprehensive approach to screening for developmental delay
- Recognizes that there are many experts in a child’s life
- Recognizes that care should be delivered in a family centered approach
- Coordinates resources and avoids duplication of services
- Helps ensure seamless transition from screening, referral and follow up
- Applies the concepts central to medical home creating a comprehensive developmental screening program

www.healthychildcare.org

What if screening is done in multiple settings

- You are duplicating services. This costs must be considered including the opportunity cost
- The authors of the ASQ recommend best practice as screening at 4 to 6 month intervals
- If one interval falls into the concerning zone you need to refer, not repeat
- Repeating what was done elsewhere risks affecting the relationships between screening entities and families
Risks of screening in multiple settings

- The more you screen for any condition, the more increased false positive and decreased false negative results you get.
- There is a risk of getting "pseudo-disease."
  - Examples include cervical cancer.
- Opportunity Costs—If you are duplicating screening efforts, what is lost as a result?

What is the ideal system

- One that puts the child and family in the center.
- One in which all children are screened three times before age 3 years.
- One in which all children identified as having a risk for delay are referred.
- One in which all children referred go through evaluation.
- One in which all referrals made are followed up on.
- One in which all experts in the child’s life are aware of the referral and can support the family.
- One that allows for easy transitions for the family and fully supports the child and family in all aspects.

Where Do You Fit Into the Ideal System?

- Ask...
  - Why are we screening?
  - Parent Education?
  - Connect families with services?
  - Increase detection rates?
  - Do these goals require a standardized developmental screening tool?
  - Do the benefits outweigh the risks?
  - What role can we play in surveillance?

What is your Role

- Developing community partnerships.
- Building a strong foundation.
- Carrying out well defined and organized physician outreach.
- Clearly defining the referral and follow up processes.
- Making parent education a priority.
- Organizing community training efforts.
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