

Overcoming Barriers to Referral and Care Coordination for Children Eligible for Early Intervention Services



**February 3, 2009
3:00 PM Eastern**

Please hold until Jill Rosenthal and Ed Schor start the conference.

**For audio, please dial:
(866) 740-1260
ID: 8223913**

This event is supported by The Commonwealth Fund.

Overcoming Barriers to Referral and Care Coordination for Children Eligible for Early Intervention Services



Scott G. Allen, Executive Director, Illinois Chapter, American Academy of Pediatrics
February 3, 2010

Emphasis on Screening, Referral

- Lack of formal screening
 - 15-50% use validated tools, often selectively^{1,2}
 - 64% not using tools, only 30% refer to EI (IL)³
- Movement toward universal screening
 - AAP policy statement
 - ABCD projects
 - NASHP Screening Academy
- Significant progress in Illinois

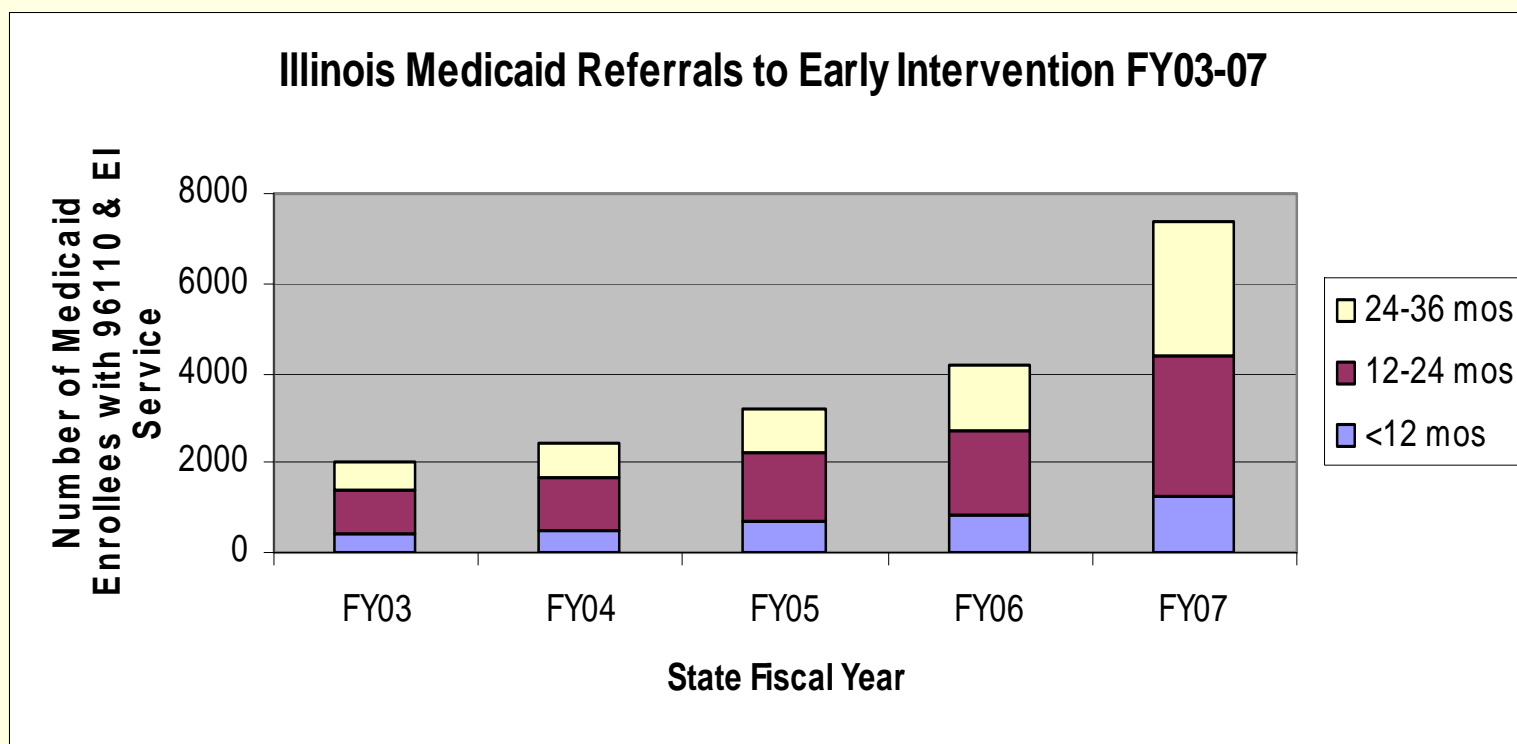
1. *Pediatricians' Reported Practices Regarding Developmental Screening*, Pediatrics, July 2005

2. *Developmental Screening in Primary Care*, Commonwealth Fund, Dec 2007

3. *Unmet Needs Project*, UIC/Erickson Institute, May 2002

Illinois Experience

Referrals to Early Intervention



Referral Results in New Challenges

- Challenges in communication
 - Busy practices, overburdened EI systems
 - Cultural divide¹
 - Medical: acute orientation, patient focused, hierarchical
 - EI: long-term, family support, systems oriented
 - Communication tools, increase in depth of understanding needed
- Practices need to:²
 - Meet with local agency representatives
 - Identify individuals to facilitate referrals
 - Receive reports on status of referrals

1. *Understanding Institutional Functional Style*, Infants and Young Children, January 1990

2. *Improving the Delivery of Health Care that Supports Young Children's Healthy Development* (ABCD II Report), The Commonwealth Fund, February 2008

Referral Results in New Challenges

- Parent Experience¹
 - 7.5-month gap between diagnosis and IFSP
 - Lack of coordination between agencies, pediatrician reluctance potential factors
 - 22% of families wanted more involvement in decision making
 - 20% not aware of written plan^{1,2}
 - Call for “models, practices and professional skills” more supportive of families

1. *First Experiences with Early Intervention*, Pediatrics, April 2004

2. National Early Intervention Longitudinal Study, January 2007

Coordinating Care Between EI and the Primary Care Medical Home

A collaborative project between Advocate Health Care Healthy Steps Program, the Illinois Chapter of the American Academy of Pediatrics, and the Illinois Early Intervention Bureau. Funded by a grant from The Commonwealth Fund.

Major Objective: improve child health outcomes by strengthening the coordination of care between Early Intervention and primary care

“Establishing an effective and efficient partnership with early childhood professionals is an important ingredient of successful care coordination for children within the medical home.”

-- Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. Pediatrics. 2006 Jul;118(1):405-20



Coordinating Care Objectives

- **increased referrals** to EI from primary care providers
- **decreased time required** for EI case coordinators to receive information from primary care practices
- **increased satisfaction** with patient referral procedures among both EI staff and primary care medical professionals
- **tool/training development**



Coordinating Care Products

■ **Trainings**

- Medical home/PCPs
- EI staff

■ **Tools**

- Universal referral and prescription forms
- IFSP summary form or check off form
- Referral logs

■ **Papers/articles**

- State EI survey
- Challenges to communication
- Project results, recommendations



Lessons to Build On

- PCPs benefit from training about EI and its services
- Practices can use strategies and tools (assigned care coordinator, referral tracking) to be better partners with EI
- Increasing personal contact between PCPs and community-based EI is crucial to increase referrals, build trust
- Understanding different PCP settings (pediatric, family practice, FQHC, residency) can help local EI offices improve communication
- Parent partners are crucial to the health care team
- Care coordination at practice helps all parties

Challenges to Address

- Lack of a standardized referral procedure
- EI staff have difficulty getting records, prescriptions from PCPs
- “Language” of EI and primary care are different
- High caseloads among EI coordinators makes efficiency essential; repeat calls to practices drains time
- Time delays in referral, evaluation, and initiation of therapies frustrate everyone and delay services
- Medical homes coordinate many different services and specialists; where does EI fit?



Progress to Date

- Multidisciplinary leadership (PCPs, child development, EI agency and front line staff)
- Surveys (state EI administrators, local EI offices)
- Focus groups/retreats of PCPs, EI
- Phone interviews of families
- Development of training, tools
- Establishment of pilot sites
- Possibility of integration into EI system



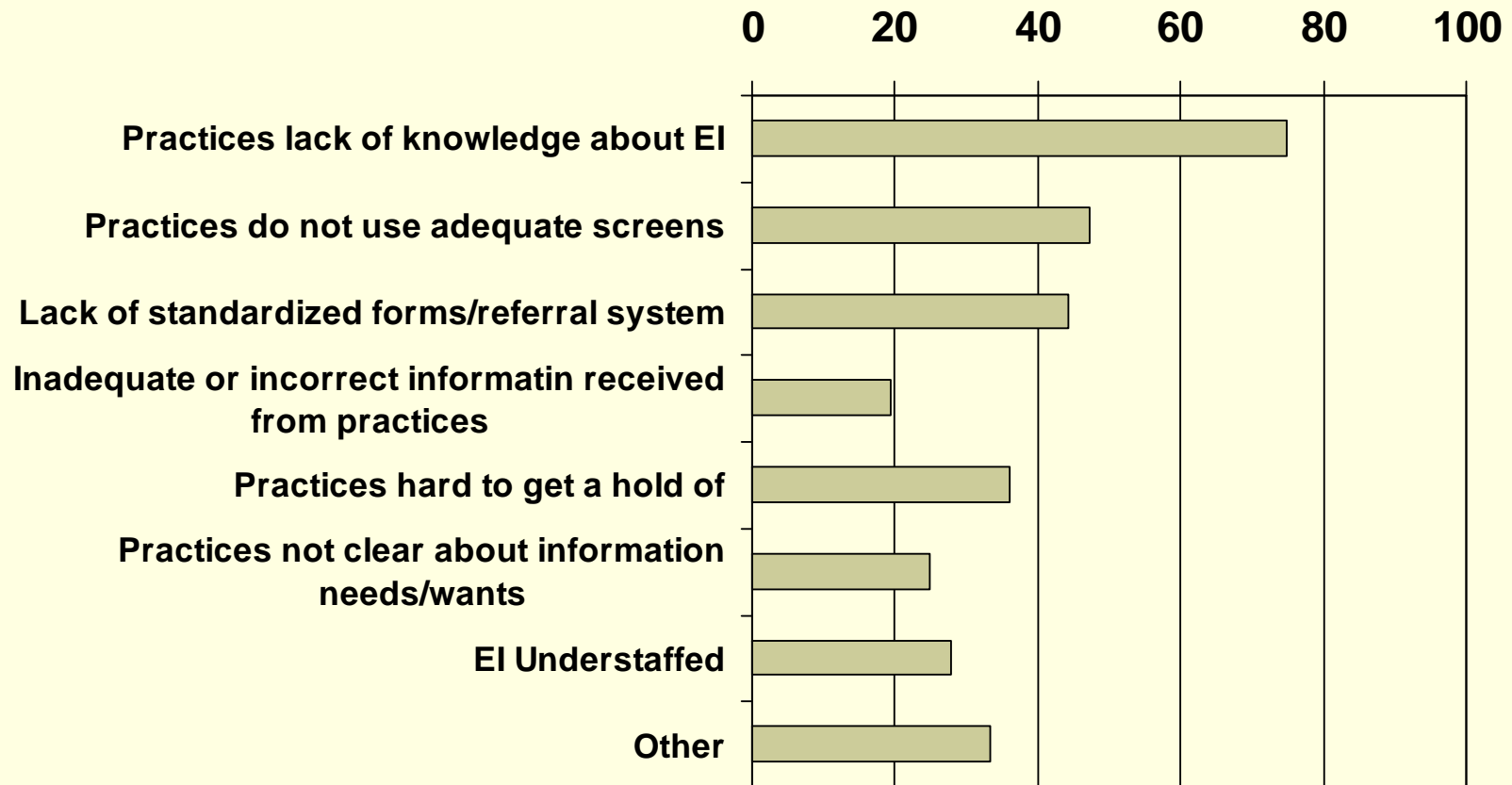
EI Surveys – National

- Many states cited ABCD/NASHP programs as progress
- Some varied outreach to PCPs cited
- 78% of states have no automated referral system

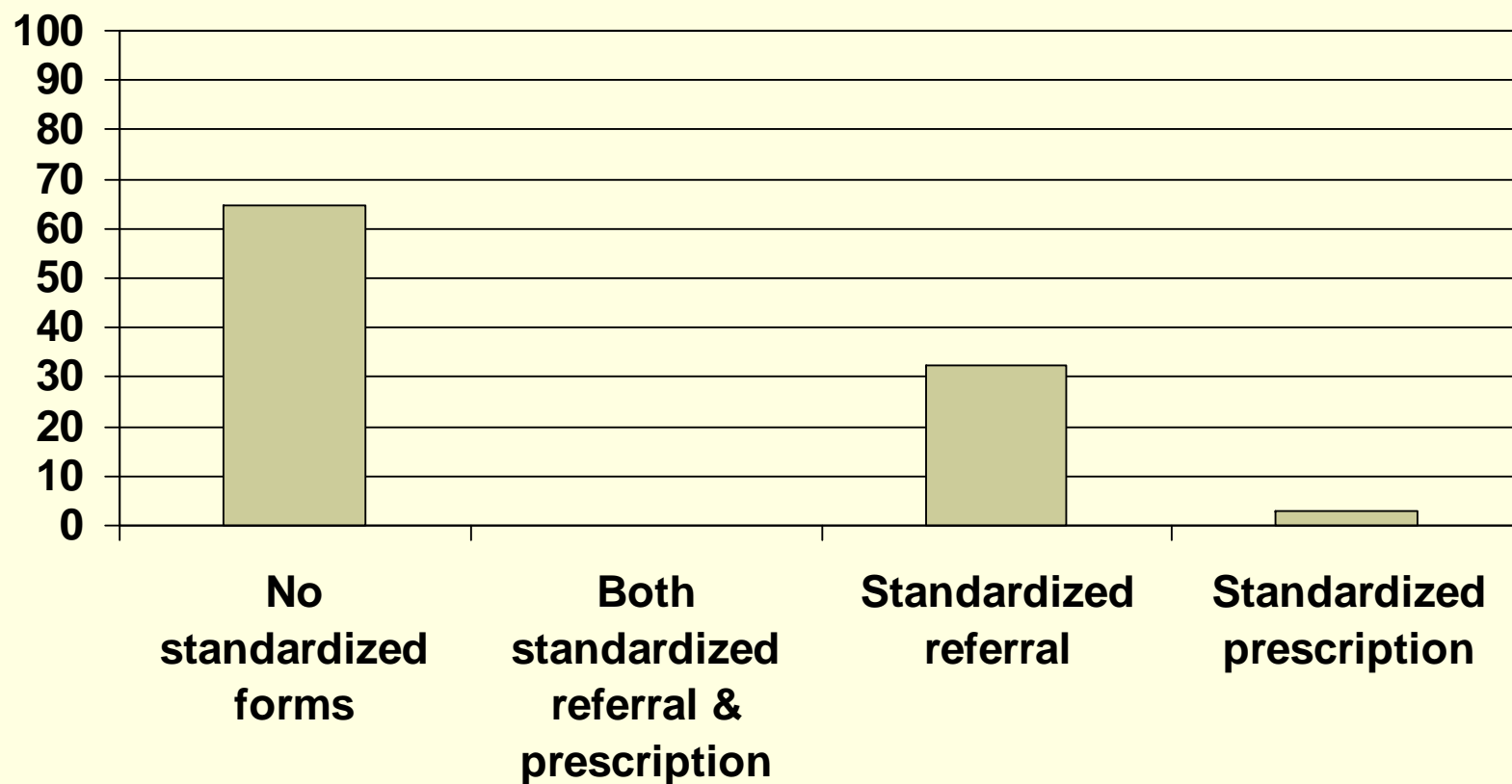
Opportunities for improvement

- Strong interest in learning more about PCPs
- 70-90% require case manager, other staff continuing education

EI Survey – National (cont'd)



EI Survey – National (cont'd)



EI Surveys - Illinois

- Illinois: 76% (19/25) local EI offices replied
 - 61% policy on working with PCPs
 - 83% policy on referrals from PCPs
 - 100% prescription policy
 - Very few of the above were *written* (1,3,8 respectively)
 - 83% have standard prescription form
 - 83% use standard referral form
 - 50-80% of PCPs use standard forms
 - 22% have had recent training on working with PCPs
 - Strong interest in learning more

EI (CFC) Focus Groups - Illinois

Universal referral/prescription forms

- Support for individual forms at local offices
- Only 10% of referrals from PCPs,
 - Little incentive to work on universal referral form
- Request for feedback on referral form irrelevant
 - CFC will provide IFSP, by law
- Prescription form more important

EI (CFC) Focus Groups - Illinois

IFSP summary form

- EI required by law to send IFSP to PCPs, prohibiting flexibility
- EI staff report developmental scores; no clinical meaning to PCPs
- Opinion split on summary sheet concept
 - PCPs' 5 questions: Was child evaluated? What did evaluation indicate? Does child need services and which? Is child eligible for EI? What follow is appropriate?

EI (CFC) Focus Groups - Illinois

Communication Challenges

- PCPs confuse EI with other programs
- PCPs refer for non-EI services
- PCPs frustrated when child is not eligible
- EI staff knew that office organization of PCPs is critical to successful referral/coordination
- Suggestions
 - EI materials to parents at PCP office, with referral
 - Parents as negotiators
 - Identify specific practice staff
 - Resources to PCP when child is not eligible

Parent Interviews

- Frustrations included:
 - Delays with scheduling EI evaluations and getting services in place
 - Transition to special education
 - Limited number of service providers.
- Quality of service providers was key to parent satisfaction

PCP/Medical Home Training

What is Free* & What is Not Free in Early Intervention

What is Free?

1. EI evaluations, both initial & follow-up
2. Basic service coordination
3. IFSP meetings
4. Transitions to school district
5. EI interpreter services
6. EI parent liaison services

What is Not Free?

1. Ongoing therapy services, including assistive technology

* = The term "free" is being used to designate items that would not be subject to family participation fee. It is possible that items would be subject to a family fee if the family's size and income would generate a family fee of \$0.

Adapted from: A Family's Introduction to EI 2007
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Communicating With EI The Service Coordinator: Your Point of Contact

- The responsibilities of a Service Coordinator include:
 - Coordinating initial & annual evaluations/assessments
 - Facilitating and participating in the development, review and evaluation of the Service Plan
 - Assisting families in identifying service providers
 - Coordinating the delivery of services identified in the Service Plan

Communicating with medical and health providers, including requests for medical records and other medical documentation from physicians, hospitals, nurses, etc.

Identify the Service Coordinator listed on the IFSP if you have questions or concerns

Example: contact the Service Coordinator if you notice changes in the medical history on the IFSP

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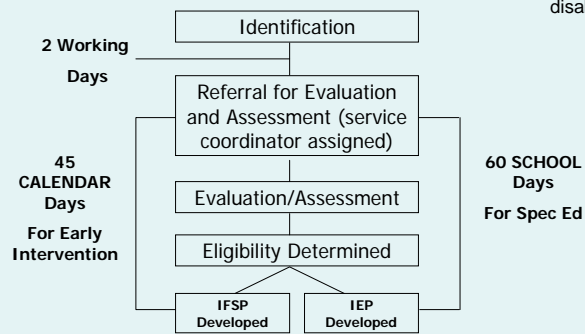
Role of Primary Care providers

- Identify delays or potential risks
- Make referrals
- Assist families to understand the referral process
- Ensure patient follow up with services they need
- Respond to identification of specific delays with medical work-up as needed
- Help families deal with potential reality of having a child with a disability

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Early Intervention: When



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Communicating With Parents

Remember: Early Intervention is voluntary. Parents have the right to decide not to participate.

- The physician should encourage families to participate in EI by:
 - Explaining the benefits of EI
 - Communicating the reasons why EI is needed
 - Explaining the referral process– who will contact them, when, what information they will need to provide
 - Addressing parents' concerns and answering questions
 - Communicating the importance of following the referral to EI

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EI/CFC Training

Medical Home: What Does It Include?

- A partnership between family and PCP
- Relationships based on trust and respect
- Connections to supports and services
- Respect for a family's beliefs
- Extended access
- Support for families in caring for their
- PCP coordinates care with other provi

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Differences Between Perspectives

EI...

- EI accepts referrals from everyone – parents, teachers, child care, etc.

Why It's Challenging for PCPs...

- Medical system more diligent about:
 - referrals being approved by and coordinated with PCPs
 - paperwork on referrals ending up with PCP office
- PCPs often unaware about their patients have been r EI

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What Do PCPs Expect When They Make a Referral

- The family will follow up on the referral
- The referral resource will read the information sent in the referral
- The referral resource will communicate findings back to the PCP via a personal letter and possibly copies of test results
- The CFC will summarize key findings in IFSP (summary)

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What Is It Like to be a PCP?

- Staff set up your daily schedule
- 5:30 am hospital rounds – see sick patients and newborns (may need to go to more than one hospital)
- 7:30 Hospital meeting, grand rounds, phone calls, review lab reports and other reports
 - 2:30 and 1:00 – see patients
 - 3 doctor schedule in a pediatric practice
 - 3 seeing 3-4 well children an hour and 3- children (some providers as many as 13 r during flu season)
 - one calls, review labs

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IFSP Summary Page Sample

Individual Family Service Plan (IFSP) Summary Form/EI Referral Follow Up

As a courtesy follow up, please note the enclosed information regarding your patient's experiences within Early Intervention.

Child's Name

Date of Birth

Today's Date

Service Coordinator (SC) SC Phone # IFSP Date (if applicable)

This child has received Early Intervention **evaluations** in the following disciplines:

General results of the Early Intervention evaluations: Developmental Therapy (DT) Speech Therapy (ST) Physical Therapy (PT) Occupational Therapy (OT) Social Work/Counseling (SW) Other

Notes:

- The child **was not found eligible** for EI services and may be re-screened within the next 3-6 mo., if developmental concerns persist.
- The child **was found eligible** for EI services. The child's IFSP team has recommended the following services: DT: x per wk mo ST: x per wk mo PT: x per wk mo OT: x per wk mo SW: x per wk mo Other: x per wk mo

This form is being piloted within the project entitled **Coordinating Care between Early Intervention and Primary Care Medical Home Practices**, a collaborative effort between the Illinois Chapter of the American Academy of Pediatrics (ICAAP) and Advocate Health Care, in cooperation with the Illinois Department of Human Services' Bureau of Early Intervention.

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Training Evaluation

- Pre/post test PCP knowledge scores increased (3.98 to 5.39 out of 6)
 - Sample: When referring a child to special education the parent needs to request the evaluation in writing, not the physician.
- High (94%) scores on content usefulness, clarity
- Highlights
 - Education on EI processes
 - Meeting local EI staff

Next Steps

- Continued evaluation of improvements in pilot sites
- Revision of training, materials
- Approval of training for EI staff as part of EI continuing education
- Spread training for EI/CFCs
 - development of internal experts
- Development of web-based training for PCPs



Preliminary Lessons

- Interest in improving coordination is there
- Both groups can improve
 - EI can make some systematic improvements (ie, official training for staff)
 - PCPs may have larger challenge: improving practice systems, understanding EI, and communicating effectively with parents
- “Universal” tools, short forms not likely to be the solution
- Community level, relationship building is still key
- Some barriers not addressed (ie transition to special education)

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Discussion

*Please be sure to take your phone off of mute before speaking.
You may also type in a question in the chat box.*