What Providers Understand about the ASQ, the Referral Process and Parents’ Fears

An Extension of the First Connections Developmental Screening Initiative

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The Developmental Screening Process

- Recommended since 2001 and reinforced in 2006 by the AAP
- Increasing prevalence of universal screening
  - 23% of pediatric offices used screens in 2002
  - Increased to 70% by 2012
- Multiple studies have looked at barriers to evaluation and referral
- When data is collected and examined, up to 50% of referrals to early intervention (EI) are not completed
  - versus 33% of other pediatric referrals not being completed
- The next step is to see how effectively providers are communicating with families, as measured by EI linkage
Study Design

• **First 5 LA** funded a 3 year grant for **First Connections** to initiate developmental screening at 7 sites starting March 2014
  – Technical assistance team: Barbara Wheeler PhD, Marie Poulsen PhD, Irina Zamora Psy.D, Marian Williams PhD

• Grant sites included: Altamed, Eisner Pediatrics, NEVHC, Foothill Family Services, Westside Children’s Center, South Central RC/FRC

• Follow up questionnaire scheduled for 2015 as part of the grant,
  – Change in practice assessment

• Expand the survey and look at what providers know or assume about the ASQ, its accuracy, and parental perceptions.
Factors were identified primarily from 2 focus group based studies, and 1 interventional study that looked at the EI referral process, both how it failed and succeeded.

9 provider factors were identified that had an influence on parents’ decision making, and might be amenable to training.

3 caregiver factors would obviously not be amenable to training, but might have different outcomes depending on provider approach.
The paper I wanted to write:

Barriers to Evaluation for Early Intervention Services: Parent and Early Intervention Employee Perspectives

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ABSTRACT

OBJECTIVE: To explore barriers to early intervention (EI) evaluation among referred infants and toddlers.

METHODS: We conducted semistructured interviews with parents of children referred for EI services and with EI staff. We purposively sampled families according to whether they received an EI evaluation. Families were recruited from a randomized controlled trial testing implementation of developmental screening. Parents filled out demographic surveys. Interviews were recorded, transcribed, and coded. We identified themes within and across respondent groups using modified grounded theory.

RESULTS: We reached thematic saturation after interviewing 22 parents whose child was evaluated by EI, 22 not evaluated, and 14 EI employees. Mean child age at first referral was 16.7 months, and 80% were referred as the result of language concerns. We identified 5 primary themes: (1) Parents reported communication problems with their pediatrician, including misinterpreting reassurance and not understanding the referral process; (2) Many parents saw themselves as experts on their child’s development and felt they should decide whether their child pursues EI services; (3) Some families preferred to wait for the developmental concern to resolve or work with their child on their own prior to seeking EI services; (4) For ambivalent parents, practical obstacles especially limited completion of evaluation, but highly motivated parents overcame obstacles; and (5) EI employees perceived that families avoid evaluation because they mistake EI for child protective services.

CONCLUSIONS: Communication between pediatricians and families that addresses practical logistics, families’ perceptions of their child’s development and EI, and motivation to address developmental concerns may improve the completion of EI referrals.

KEYWORDS: developmental delay; early childhood development; early intervention

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The Interventional Study:

Barriers to Enhancing Practice-Based Developmental Services

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KEY POINTS

- Time for and confidence in developmental monitoring in primary care practice are still perceived as barriers by providers, despite training that offered specific suggestions for overcoming these barriers.
- Training on the use of the Help Me Grow system significantly addressed provider barriers to referral, specifically concerns about available services and eligibility criteria.
- Tools, or cueing systems, for the simplest and most time-efficient monitoring of development and solicitation of parental concerns need to be developed and incorporated into practice with more rigorous effort.

Patient populations were more likely to cite confidence in their ability to do assessments as a barrier.

AAP Periodic Survey #53 also addressed identification and referral issues in pediatric practice. It was administered two years after the initial study. Similar to the earlier study, time (cited as important by 82% of respondents), lack of office staff to do screening (cited as important by 48% of respondents), and inadequate reimbursement (cited as important by 44% of respondents) were most frequently reported as barriers. Regarding referral to early intervention (EI) services, the most frequently cited barrier was lack of understanding of the EI program’s processes and procedures (cited as important by 46% of respondents), followed by lack of information about the EI program and its services (cited as important by 45% of respondents).
A Look at the Family Perspective......

Sugar-coaters and Straight Talkers: Communicating About Developmental Delays in Primary Care

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KEY WORDS
child development, developmental concerns, communication, primary care

ABBREVIATION
EI—early intervention

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WHAT'S KNOWN ON THIS SUBJECT: Revised recommendations on developmental surveillance and screening in the medical home mean that providers will increasingly need to communicate with parents about developmental concerns. Little information exists to guide providers in communicating with parents regarding this complex topic.

WHAT THIS STUDY ADDS: This study provides new information and recommendations on conceptualizing communication between parents, primary care providers, and EI specialists regarding child development and developmental concerns.
First Objective : Factor Prevalence

Factors that can be addressed with training and education

1. Can you confidently describe the EI referral process?
2. Are you comfortable talking about abnormal results?
3. Do you feel the screen is too sensitive and not specific?
4. Do you get feedback from EI?
5. Are parents fearful of legal or child protective involvement?
6. Do parents feel that they will be blamed for their child’s delays?
7. Are you confident that delays will be addressed at the next visit if the parents decide to “wait and see”? 
8. Do you discuss expected milestones with parents?
9. Is there possible harm from a false positive screen?
Second Objective: Correlation

Family refusal or deferral cannot be directly addressed with training or education.

How a provider approaches the reluctant family might be...

Hypothesis: There is a correlation between the prevalence of provider and office traits amenable to education and training and...

1. Willingness to accept a “wait and see” approach
2. Confidence in ability to convince a reluctant family to get an EI evaluation
3. Likelihood of using a reassuring approach when discussing an abnormal screen.
Importance:

- Up to half of recommended EI evaluations do not happen
- Time is of the essence for these kids
- Increased refusal rates mean more work for the office
- EI linkage rates may become a quality measure
- Knowing a family’s potential point of view helps make the ASQ the starting point of a discussion rather than a simple screen.
- If families do not follow up, we cannot demonstrate screening effectiveness.
Topics for Future Research

• Retrospective chart review correlating EI referral completion and provider knowledge and opinion base
• Is there a difference in rates of EI linkage depending on the possible diagnosis (cognitive vs motor delay)?
• Why are intellectual disabilities less likely to be referred than gross motor disabilities?
• Is there any significant harm inherent to developmental screening?
• Demonstration of screening effectiveness
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Developmental Screening and Linkage Provider Survey

Your input will help us learn about providers’ experiences related to developmental screening of young children and linkage to early intervention. The survey takes about 10 minutes and is anonymous.

I. Background Questions

1. Do you provide some type of direct services to children younger than 6 years?
   - Yes  - No  (If no, please do not complete the rest of the survey. Thanks!)

2. Which agency do you work for?
   - AltaMed other than CHLA (specify site(s): ____________________________)
   - Children's Hospital Los Angeles UCEDD/Mental Health
   - Children’s Hospital Los Angeles AltaMed/GPS
   - Eisner Pediatric (specify site(s): ____________________________)
   - Foothill Family Services
   - Northeast Valley Medical Corp (Specify site(s): ____________________________)
   - South Central Los Angeles Regional Center Family Resource Center
   - Westside Children’s Services
   - Other (specify): _______________________________________________________

3. What is your specialty, job role or area of training?
   - Case Manager
   - Child Care Staff
   - Family Practice Physician
   - Medical Resident
   - Nurse Practitioner
   - Pediatrician
   - Physician Assistant
   - Psychologist
   - Social Worker or MFT
   - Teacher
   - Other (specify): _______________________________________________________

4. Are you fluent in a language other than English? If so, what language(s): ________________

II. Your Training and Experience regarding Developmental Screening

5. Did you receive training on developmental screening tools in your professional education (e.g. college, graduate/medical school, residency, internship, fellowship, etc.)?
   - Yes  - No

6. Did you attend a developmental screening training as part of the First Connections grant?
   - Yes  - No  - Not sure
7. Did you attend a developmental screening training in the past 5 years such as continuing education or on-the-job training?

☐ Yes  ☐ No

8. Have you had experience with a child of a friend, family member, or your own child being diagnosed with a developmental delay or disability?

☐ Yes  ☐ No

III. Your Current Practices regarding Developmental Screening

9. When working with children age 5 years and younger, do you screen for developmental delays?

☐ Always  ☐ Often  ☐ Sometimes  ☐ Rarely  ☐ Never

10. Do you use a formal, standardized screening tool (e.g., ASQ, PEDS, MCHAT, etc)?

☐ Always  ☐ Often  ☐ Sometimes  ☐ Rarely  ☐ Never

11. Please check any of the following roles that you have had related to developmental screening tools in the past 6 months (check all that apply)

☐ Helping parent complete screening measure
☐ Scoring measure
☐ Interpreting results of measure
☐ Reviewing results of screening with parents
☐ Giving parents written information about development
☐ Referring children for further assessment
☐ None of the above

12. How comfortable are you discussing abnormal developmental screening results with families?

☐ Very Uncomfortable  ☐ Somewhat Uncomfortable  ☐ Neutral  ☐ Somewhat Comfortable  ☐ Very Comfortable
13. How confident do you feel explaining to a family the process for starting Early Intervention services for their child (how to make the appointment, what to expect from the evaluation, and what services might be available)?

- [ ] Not at all Confident
- [ ] Slightly Confident
- [ ] Moderately Confident
- [ ] Very Confident
- [ ] Extremely Confident

14. How confident are you that you will receive follow up information from Early Intervention services regarding children that you refer?

- [ ] Not at all Confident
- [ ] Slightly Confident
- [ ] Moderately Confident
- [ ] Very Confident
- [ ] Extremely Confident

15. How confident are you that your agency will take care of the paperwork and follow up necessary to have a referral completed?

- [ ] Not at all Confident
- [ ] Slightly Confident
- [ ] Moderately Confident
- [ ] Very Confident
- [ ] Extremely Confident

16. How confident are you that parents who take a “wait and see” approach to their child’s abnormal developmental screen will be screened again at their next visit to your agency?

- [ ] Not at all Confident
- [ ] Slightly Confident
- [ ] Moderately Confident
- [ ] Very Confident
- [ ] Extremely Confident

IV. Your Opinions Regarding Developmental Screening Approaches

17. How accurate are standardized developmental screening measures?

- [ ] Consistently Overestimate Delays
- [ ] Occasionally Overestimate Delays
- [ ] Is Usually Accurate
- [ ] Occasionally Underestimate Delays
- [ ] Consistently Underestimate Delays
- [ ] No opinion

18. Have you used the Milestones Moments Booklet developed by Learn the Signs, Act Early?

- [ ] Yes
- [ ] No
19. If you have used the Milestones Moments Booklet, do you think:

18a. The information is family-centered and culturally and linguistically sensitive.

- [ ] Strongly Disagree
- [ ] Disagree
- [ ] Neutral/Not Sure
- [ ] Agree
- [ ] Strongly Agree

18b. Parents read and use the booklet to learn about their child’s development.

- [ ] Strongly Disagree
- [ ] Disagree
- [ ] Neutral/Not Sure
- [ ] Agree
- [ ] Strongly Agree

20. If I try to refer a family for an Early Intervention evaluation and the family declines, there is little I can do to change their mind.

- [ ] Strongly Disagree
- [ ] Disagree
- [ ] Neutral/Not Sure
- [ ] Agree
- [ ] Strongly Agree

21. It is ok for a family to take a “wait and see” approach when a developmental screen is abnormal.

- [ ] Strongly Disagree
- [ ] Disagree
- [ ] Neutral/Not Sure
- [ ] Agree
- [ ] Strongly Agree

22. When a developmental screen is abnormal, I usually take a reassuring approach in talking about it with the parents.

- [ ] Strongly Disagree
- [ ] Disagree
- [ ] Neutral/Not Sure
- [ ] Agree
- [ ] Strongly Agree

23. If an evaluation for Early Intervention does NOT confirm a developmental delay, what is the impact on the family of going through the evaluation (not counting time, effort and expense)?

- [ ] Greatly Harmed
- [ ] Somewhat Harmed
- [ ] Neither Harmed nor Helped
- [ ] Somewhat Helped
- [ ] Greatly Helped

V. Views Expressed by Parents Regarding Developmental Screening

24. Do parents express that they feel guilty or blamed for their child’s delayed development?

- [ ] Always
- [ ] Often
- [ ] Sometimes
- [ ] Rarely
- [ ] Never
25. Do parents express concerns that a referral to Early Intervention involves Child Protective Services?

- Always
- Often
- Sometimes
- Rarely
- Never

26. Do parents express concerns that a referral to Early Intervention involves the immigration system, or puts them at risk of deportation?

- Always
- Often
- Sometimes
- Rarely
- Never

VI. Working with Non-English-speaking Families.

27. When a parent’s primary language is not English, what advice do you give them about what language(s) to speak to their child?

- Encourage them to speak English to their child as much as possible
- Encourage them to speak their native language to their child
- Encourage them to use both English and their native language when speaking to their child
- Do not give advice and/or refer them to someone else to answer
- This question has not come up in my work with families
- Other advice (specify): _______________________________________________________

28. When a parent’s primary language is not English, and their child has a developmental disability or delay, what advice do you give them about what language(s) to speak to their child?

- Encourage them to speak English to their child as much as possible
- Encourage them to speak their native language to their child
- Encourage them to use both English and their native language when speaking to their child
- Do not give advice and/or refer them to someone else to answer
- This question has not come up in my work with families
- Other advice (specify): _______________________________________________________

29. If a child has a speech delay or other developmental delay or disability, what is your opinion about being raised in a bilingual or non-English-speaking household?

- The child is likely to have greater delays as a result of exposure to more than one language
- The child is likely to have better language skills as a result of exposure to more than one language
- Being exposed to more than one language at home will not affect the child’s overall speech and language skills
VII. Training Opportunities

30. If you would like additional training about the developmental assessment and referral process, what topics would be helpful?

______________________________________________________________________________
______________________________________________________________________________

31. Please review the Research Information Sheet attached to this survey. Can we use your survey responses (with no names or other personal identifying information included) in the research project?

☐ Yes, you may use my survey responses for research
☐ No, please do not include my survey responses in research

Thank you!