



CALIFORNIA LEADERSHIP  
EDUCATION IN  
NEURODEVELOPMENTAL  
DISABILITIES



USC University of  
Southern California

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

## An Extension of the First Connections Developmental Screening Initiative

**Chris Moore, MD**

**CA-LEND Leadership Track Research Project  
Advisor, Marian Williams PhD**

# 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.

## Study Design : Continued

- 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

*Manuel E. Jimenez, MD; Frances K. Barg, PhD, MEd; James P. Guevara, MD, MPH; Marsha Gerdes, PhD; Alexander G. Fiks, MD, MSCE*

From The Robert Wood Johnson Foundation Clinical Scholars Program (Dr Jimenez), Department of Pediatrics (Drs Guevara, Gerdes, and Fiks), Department of Family Medicine and Community Health (Dr Barg), Perelman School of Medicine, University of Pennsylvania, and PolicyLab: Center to Bridge Research, Practice, & Policy (Drs Guevara, Gerdes, and Fiks), and Division of Child Development, Rehabilitation, and Metabolic Disease (Dr Jimenez), Children's Hospital of Philadelphia, Philadelphia, Pa  
Address correspondence to Manuel E. Jimenez, MD, The Robert Wood Johnson Foundation Clinical Scholars Program, 423 Guardian Drive, 13th Floor, Blockley Hall, Philadelphia, PA 19104 (e-mail: jimenzm@emailchop.edu).  
Received for publication May 2, 2012; accepted August 21, 2012.

### 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

**ACADEMIC PEDIATRICS** 2012;12:551-557

# The Interventional Study :

0196-206X/06/2701-0030

DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS  
Copyright © 2006 by Lippincott Williams & Wilkins, Inc.

Vol. 27, No. 1, February 2006  
Printed in U.S.A.

## Barriers to Enhancing Practice-Based Developmental Services

LISA HONIGFELD, Ph.D.  
KATHLEEN MCKAY, Ph.D.

### 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 cuing 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<sup>2</sup> 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

**AUTHORS:** Laura Sices, MD, MS,<sup>a</sup> Lucia Egbert, BA,<sup>b</sup> and Mary Beth Mercer, MPH<sup>c</sup>

<sup>a</sup>*Department of Pediatrics, Division of Child Development, Boston Medical Center/Boston University School of Medicine, Boston, Massachusetts;* <sup>b</sup>*Department of Maternal and Child Health, School of Public Health, Boston University, Boston, Massachusetts;* and <sup>c</sup>*Department of Bioethics, Cleveland Clinic, Cleveland, Ohio*

### KEY WORDS

child development, developmental concerns, communication, primary care

### ABBREVIATION

EI—early intervention

The content of this article is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

[www.pediatrics.org/cgi/doi/10.1542/peds.2009-0286](http://www.pediatrics.org/cgi/doi/10.1542/peds.2009-0286)



**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.

abstract

## 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**

# Acknowledgements

- Marian Williams PhD
- First Connections Training and Technical Assistance team, Barbara Wheeler PhD, Marie Poulsen PhD, Irina Zamora PsyD
- Douglas Vanderbilt MD, Sheela Rao MD, Carolina Pena-Ricardo MD
- Christine Park MD, MPH, CLE, FAAP, - Medical director of Pediatrics NEVHC
- Debbie Rosen - Director of Quality and Health Education NEVHC
- Cynthia Jimenez - Program Coordinator NEVHC
- Adilene Hernandez - Care Coordinator NEVHC
- Sheree Schrage PhD

# Acknowledgements

- Marian Williams PhD
- First Connections Training and Technical Assistance team, Barbara Wheeler PhD, Marie Poulsen PhD, Irina Zamora PsyD
- Douglas Vanderbilt MD, Sheela Rao MD, Carolina Pena-Ricardo MD
- Christine Park MD, MPH, CLE, FAAP, - Medical director of Pediatrics NEVHC
- Debbie Rosen - Director of Quality and Health Education NEVHC
- Cynthia Jimenez - Program Coordinator NEVHC
- Adilene Hernandez - Care Coordinator NEVHC
- Sheree Schrage PhD

## References

- Jimenez ME, Fiks AG, Shah LR, et al. Factors associated with early intervention referral and evaluation: a mixed methods analysis. *Academic pediatrics*. 2014;14:315-323.
- Jimenez M, Barg F, Guevara J, Gerdes M, Fiks A. Barriers to Evaluation for Early Intervention Services: Parent and Early Intervention Employee Perspectives. *ACADEMIC PEDIATRICS*. 2012;12:551-557.
- Sices L, Egbert L, Mercer MB. Sugar-coaters and Straight Talkers: Communicating About Developmental Delays in Primary Care. *Pediatrics*. 2009;124:e705-E713.
- Honigfeld L, McKay K. Barriers to enhancing practice-based developmental services. *JOURNAL OF DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS*. 2006;27:S30-S33.
- Radecki L, Sand-Loud N, O'Connor K, Sharp S, Olson L. Trends in the Use of Standardized Tools for Developmental Screening in Early Childhood: 2002-2009. *Pediatrics*. 2011;128:14-19.
- Larson J, dosReis S, Stewart M, Kushner R, Frosch E, Solomon B. Barriers to Mental Health Care for Urban, Lower Income Families Referred from Pediatric Primary Care. *Administration and Policy in Mental Health and Mental Health Services Research*. 2013;40:159-167
- Arunyanart W, Fenick A, Ukritchon S, Imjaijitt W, Northrup V, Weitzman C. Developmental and Autism Screening A Survey Across Six States. *INFANTS & YOUNG CHILDREN*. 2012;25:175-187