Hindsight is 20/20

Are families getting the EI services they need?

Presented by Lisa Crawford
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Learning Objectives:

- Explain why some parents may not be satisfied with their EI services and address perceived and/or real gaps in service.
- Discuss why some families decline EI services.
- Identify strategies to explain the benefits to parents of enrolling in EI services.
5.) Early intervention

- All families of infants with any degree of bilateral or unilateral permanent hearing loss should be considered eligible for early intervention services.

- There should be recognized central referral points of entry that ensure specialty services for infants with confirmed hearing loss.

*Joint Committee on Infant Hearing*
2007 JCIH Position Statement: Highlighted Updates

5.) Early intervention (con.)
   - Early intervention services for infants with confirmed hearing loss should be provided by professionals who have expertise in hearing loss, including educators of the deaf, speech-language pathologists, and audiologists.
   - In response to a previous emphasis on “natural environments,” the JCIH recommends that both home-based and center-based intervention options be offered.
2007 JCIH Position Statement: Highlighted Updates

7.) Communication

- The birth hospital, in collaboration with the state EHDI coordinator, should ensure that the hearing-screening results are conveyed to the parents and the medical home.

- Parents should be provided with appropriate follow-up and resource information, and hospitals should ensure that each infant is linked to a medical home.
7. Communication (con.)

- Information at all stages of the EHDI process to be communicated to the family in a culturally sensitive and understandable format.

- Individual hearing-screening information and audiology diagnostic and habilitation information should be promptly transmitted to the medical home and the state EHDI coordinator.

- Families should be made aware of all communication options and available hearing technologies (presented in an unbiased manner). Informed family choice and desired outcome guide the decision-making process.
4 of 8 - The EHDI system should be family centered with infant and family rights and privacy guaranteed through informed choice, shared decision-making, and parental consent in accordance with state and federal guidelines. Families should have access to information about all intervention and treatment options and counseling regarding hearing loss.

Source: JCIH 2007 Position statement – updated principles, pg. 900
2007 J CIH Principles

7 of 8 - Appropriate interdisciplinary intervention programs for infants with hearing loss and their families should be provided by professionals who are knowledgeable about childhood hearing loss. Intervention programs should recognize and build on strengths, informed choices, traditions, and cultural beliefs of the families.

Source: J CIH 2007 Position statement – updated principles, pg. 900
Parent Survey

- 55+ completed surveys
- Participants mainly from National H&V network and TX parents
- Parents with children of all ages
- Case studies from TX FTG program
Survey results: Age of child

- Birth to 3 yrs. – 12 responses (22%)
- 3 to 5 yrs. - 12 responses (22%)
- 5 to 12 yrs. – 21 responses (38%)
- 12+ yrs. – 10 responses (18%)
Survey results: Age of ID

- Birth to 6 mos. – 31 (56%)
- 6 to 12 mos. - 3 (5%)
- 13 to 18 mos. – 11 (20%)
- 19 to 24 mos. – 0
- 25 to 35 mos. – 2 (4%)
- 36 mos. or older – 9 (16%)
Survey results:
Received EI services?

- Yes - 46 (84%)
- No - 9 (16%)
Survey results:
Rating of services received

- Excellent – 26 (47%)
- Above Average – 9 (16%)
- Average – 6 (11%)
- Below Average – 2 (4%)
- Poor – 3 (6%)
Reasons for ratings of “average” or below (summarized):

- No choices/options given – told what they would get
- Multiple evaluations to determine eligibility – enrollment delays
- Providers pushing their opinions
- Low expectations
Reasons for ratings of “average” or below (summarized):

- Service coordinators and/or providers unknowledgeable about deafness/hearing loss
- Poor communication and follow-up. Parent had to contact EI multiple times
- Favoritism shown towards families with specific ethnic background
What didn’t you understand about your services?

- Did not understand all the options – they were not explained in full.
- Not given a complete list of communication options.
- Wasn’t sure who pays for services.
What didn’t you understand about your services?

- Difficult to understand service delivery and all the various therapies
- We were excluded from other families and H&V – not sure why.
- It was assumed I wanted mainstreaming for my child. Other options were not given.
What would have helped you understand EI services better?

- “Someone with experience with HL children knowledgeable about current technology and appropriate EI services to maximize potential.”
- Communication and program options explained.
- Time helped – “too hard to grasp it all in the beginning.”
What would have helped you understand EI services better?

- More explanation during the intake process about what to expect.
- Time – “most parents don’t care what EI is until they need it, and then it’s a learning process.”
- ‘Someone who knew more about hearing loss and the problems associated with it’
Survey handout

- Survey questions provided
Why some families refuse service

- Case studies
Strategies to improve parent understanding of EI services

When services are offered:

- Referral phone calls – script WITH training example (before and after parent feedback)
- Build trust – don’t try to share everything at once
- The “Invisible” disability – explain why services are needed.
- Eligibility- support during the ID process

Discussion- other ideas?
Strategies to improve parent understanding of EI services

When services are initiated:

- Initial overview of therapies, placements and communication options
- Ongoing review of information/IFSP
- Connections with other families
- Discussion – other ideas?
Thank you!

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