Scripting the Message in 2011 for the One, Three, Six Goals

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Why Should We Script Our Messages?

• Expectation that a typical sequence of events will occur for all families
  – Timely and detailed information
    » Written and verbal facts
    » Culturally sensitive information
    » Family centered
  – Motivated to take necessary next steps
  – Infant receives timely follow-up care
  – Outcomes improve
  – EHDI goals and objectives are met
Integrated Framework for Developing Scripted Protocols and Procedures

• Chapter 243 of the Acts of 1998
• DPH Advisory Committee
  – Active constituency/supports EHDI
• Hospital Licensure Regulations and Guidelines
• Audiological Diagnostic Center Guidelines
• Protocol checklists and review summaries
• Designated program goals and objectives
• Evaluation criteria
Messaging for EHDI

• Perception of EHDI
  - Nationally
  - State specific

• How does a state create the message?
  - Pregnant women and families
  - Hospitals
  - OB offices
  - Midwives
  - Individual screeners
  - PCP’s
  - Audiologists
Process in Massachusetts

- Electronic Birth Certificate
- Families leave the hospital with an appointment at an approved center
- Family contact
  - Not ‘a script’ but is ‘scripted’
  - 8 areas to cover, if possible
  - PCPs receive phone calls/faxes/letters
  - Message is ‘this is important and time sensitive’
- Average age of babies to receive a dx test for all refers (unilateral and bilateral) is just over 4 weeks
Process Continued

• Branded state specific resources
  – Parent Information Kit, provided by diagnostic audiologist at the time of diagnosis
  – Messages from the diagnostic audiologist is reinforced by the Kit
    • ‘Make the connection to Early Intervention’
  – Parent of a child with hearing loss on staff reviews Kit with family over the phone, provides family support

• Enrollment rate for children with hearing loss into Early Intervention is 80% (documented enrolled)
Family Satisfaction

• Surveyed families whose children had been screened (regardless of results and outcome) and asked questions about their experience.
• Excellent tool to identify areas of improvement in the program
• Ultimately, over 99% of families said that if they had another baby they would want their hearing to be screened
Scripting Results

- 100% birth facilities and ADCs have written screening protocols
- Families received consistent messages through materials and PIK
- EHDI Goals and Objectives are met
  - >99.5% infants screened
  - 1,405 referred (1.8%)
  - 202 children diagnosed with hearing loss (83.7% before 3 months of age)
  - 4.2% lost to follow-up
  - 100% of families received parent to parent support at diagnosis and Parent Information Kit

*MA EHDI Data 2008
# Age (in months) at diagnosis of hearing loss

<table>
<thead>
<tr>
<th>Year of Birth</th>
<th>Number Diagnosed with Hearing Loss</th>
<th>Median Age at Diagnosis (in months)</th>
<th>Average Age at Diagnosis (in months)</th>
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<tbody>
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<td>2004</td>
<td>225</td>
<td>1.15</td>
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<td>2005</td>
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<td>1.13</td>
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<tr>
<td>2008</td>
<td>202</td>
<td>1.10</td>
<td>1.90</td>
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Partnering for the Success of Children with Hearing Loss

• Impetus for the initiative
  • 2006 EHDI-PART C Meeting
• Addressing the barriers
  • What is unique about children with hearing loss?
• Moving beyond geography, bias, past practice
Making it Happen In Massachusetts

• Community forums
  – Stakeholders: MA Commission for the Deaf and Hard of Hearing, parents, six schools for the deaf, teachers of the deaf, deaf adults, SLPs, Cochlear Implant specialists, audiologists, early childhood educators, EI programs, EHDI program
  – Focus groups for parents of young children with hearing loss
  – What are system needs? What are professional competencies?

• Partnering for the success of children with hearing loss task force
  – Stakeholders in advisory capacity to Department of Public Health
Incorporated principles and perspectives from existing guidelines

Developed recommendations in seven areas:

- Infants + young children with HL and their families need immediate access to expertise of professionals knowledgeable about hearing loss

- Professionals provide families complete and unbiased information about hearing loss, communication development, importance of early access to language, available hearing technologies

- Parents are provided with information and services specific to the unique needs of children with HL and strategies that promote their child’s development
Task Force Report Continued

• Access to the range of communication approaches is available regardless of where the family lives

• Families are provided with a variety of options to meet their needs for support and information

• Transition from IDEA Part C to Part B services is seamless + provides children with HL access to educational programs that provide communication assessment, access, and development as well as addressing academic and social needs

• Service providers are knowledgeable about the unique educational needs of young children with HL and the need for content specific information for their parents and caregivers
EI Contacts

• Marketing

• Responsibilities

• Training
Maintaining Momentum

• UNHS Program support
• Regional meetings of EI contacts
  • Local presenters for content and context
• List serve to share info and issues
Questions?