Communication Options: Supporting Families in Navigating the Controversies

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Overview

• Decision making processes
• Communication options re-conceptualized
• Physician roles in supporting families
• Resources for further information
Goals of Early Intervention

• Support family in creating a language rich environment
• Capitalize on sensitive periods
• Promote healthy emotional context for development
• Support family learning and decision making
Decisions...decisions

- Families face several complex decisions
  - During period of intense adjustment
- Beyond communication options...
  - program choices/features
  - family roles
  - hearing aid technologies
  - medical considerations
And to complicate matters…

• Lack of consensus among professionals
  – About best practices

• Advancing technologies
  – lags in documentation of advantages for infants (bilateral CI)
  – “moving targets” complicate interpretation of existing evidence
  – may feel pressure to make choices to capitalize on sensitive periods$^1$
Methodology Continuum

Auditory - Verbal  Auditory - Oral  Cued Speech  Total Communication  ASL

AUDITORY  VISUAL

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Auditory Verbal

• Guide, counsel & support parents as **primary models** for spoken language
• Help children integrate **listening** into development of communication and social skills
• Auditory-verbal development through 1 to 1 teaching
• Families expected to develop listening and **language rich environment** for child

More info:  www.agbell.org
Auditory-Oral

- Encourages maximum use of residual hearing and hearing technologies
- **Auditory** learning focus +
- **Visual** supports (speech reading) to aid communicative development
- Families encouraged to create optimal oral learning environment
- High expectations for **spoken language**

More info:  www.agbell.org
Cued Speech

• Visual communication system
  – _eight handshapes in four different placements near the face_
  – _+ mouth movements_
  – _make the sounds of spoken language look different from each other (mom, Bob, pop)_

• Supports spoken language learning & literacy; adverse listening situations

• Families learn to use the system through workshops and practice

More info: www.cuedspeech.com
Total Communication

- Combines all means to communicate with the child
  - Signs (English-based signing system)
  - Listening, Speechreading
  - Natural gestures
  - Body language
- Encourages simultaneous use of speech & sign to promote access to spoken language
- Families must gain sign fluency and consistently sign when speaking
ASL/Bilingual-Bicultural

• Deaf children learn ASL as the primary language
  – English is learned as a second language once ASL is mastered
• Prepares child for social access to the Deaf Community
• Family learns about Deaf culture; invest in learning ASL; provide child access to fluent users of ASL
• Devices may or may not be emphasized

For more information:
http://clerccenter.gallaudet.edu/
### Varying Perspectives

<table>
<thead>
<tr>
<th>What they share</th>
<th>Where they differ</th>
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</thead>
<tbody>
<tr>
<td>• Desire to maximize language development</td>
<td>• Methods to achieve goals</td>
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<tr>
<td>• Provide language rich environment</td>
<td>• Vision for the future</td>
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<tr>
<td>• Support for literacy</td>
<td>• View of the role of visual support/language</td>
</tr>
<tr>
<td>• Support families in their roles as primary language models</td>
<td>• Value placed on devices/speech production</td>
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Methodology reframed

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Shifts the Focus…

- From program philosophy
- To child’s learning needs
- And a dynamic view of learning
  - Requires ongoing evaluation
- Recognizes the consistent finding of wide ranges in performance outcomes
Variables Affecting Progress

- Age at diagnosis
- Etiology
- Device use & effectiveness
- Auditory learning abilities
- Health status of child
- Personal-social adjustment of family
- Family involvement
- Skills of the service providers
- Parenting Skills
- Child’s temperament & learning styles
- Intellectual abilities; secondary disabilities
- Cultural values
- Socioeconomic issues

Estabrooks, 1996
Children with CIs

• Some CI teams require AVT or spoken language programs
  – Does this limit parental decision making authority?
  – Will all children succeed in the approach?

• Factors associated with positive outcomes
  – Age at implantation $^2$
  – Pre-implant use of residual hearing$^2$
Children with CIs

• Signing and CIs – Evidence is mixed
  – Higher levels of speech & language associated with programs that are highly auditory\(^3, 4\)
  – Yet, recent studies show that early implanted children quickly transition from sign to spoken language\(^5, 6\)
  – Families will consider varying ways to promote communication access in year 1
Considerations in Decision Making

- Family values and goals
- Community resources
- Family resources (what level of commitment?)
- Timing of the information
- Finding unique “fit”
  - May change as the child’s needs change
  - Adaptable approach with “safety nets”
  - Program features and expectations
Decisions less “weighty” when...

• Not “set in stone”
  – Can be evaluated and adjusted over time
• Can be combined in creative ways to achieve a variety of goals
• Can be “tailored” to address individual needs
Key Points for Pediatricians

• Does the family have options?
  – Know your community resources
  – How to link with EI providers
  – Are specialists familiar with this population?

• Know that one method will not fit all needs
  – Process of decision making is ongoing
  – Complex, guided by the ongoing early intervention process
Key Points for Pediatricians

• Receive progress reports from early intervention
  – If developmental progress is of concern, further evaluation may be needed
• Provide input to the early intervention team about the child’s
  – Health needs
  – Developmental status
• Support families in focusing on child’s needs
Key Points for Pediatricians

• Understand the complexity of this process for families
  – Many children can learn orally
  – Some will need other kinds of supports to be successful
  – Success is the ultimate goal
• Families say they wish for:
  – Objective information to support decision making
  – Links to community resources
  – Opportunities to talk with other families
  – Respect for the choices they make

• www.handsandvoices.org
Provide Questions to Guide Families

• Do you know what the options are?
• Do you understand the options?
• Have you examined them in person?
• Do you understand all test results?
• How much time do you have to devote to learning the methodology?

Beginnings, 2002 (see chart pdf)
Most important decisions....

- Parental decision to trust in their ability to parent this child
- Decision to view the child as a capable learner

Family Resources

- [www.beginningssvcs.com](http://www.beginningssvcs.com)
- Text – Choices in Deafness – Sue Schwartz (Woodbine House, 1996)
- [www.babyhearing.org](http://www.babyhearing.org)

- For further information: moeller@boystown.org
References


