

It Takes a Village: An Interdisciplinary Model to Serve the Needs of Young Children with Hearing Loss and Their Families

K. Todd Houston,
Ph.D.

Karen Muñoz, Ed.D.

Ruth Mathers, M.S.

Department of Communicative
Disorders & Deaf Education
Utah State University
Logan, Utah





Service Provision Goal

- To provide all infants and young children with hearing loss and their families with services that are:
 - Timely
 - Comprehensive
 - Coordinated
 - Effective



EHDI Service Continuum

- Newborn Screening
- Diagnostic Assessment
- Medical Referrals
- Amplification Fitting
- Early Intervention Services
- Early Education

Parent education, support, and involvement is embedded throughout the process

Stakeholders

- Hospital nursery staff
 - Screening
- Physicians
 - Medical home/assessment/monitoring
- Audiologists
 - Screening/assessment/amplification/intervention
- Speech-language pathologists
 - Speech-language intervention
- Deaf educators
 - Intervention, education
- Early interventionists
 - Developmental intervention (e.g.; PT, OT, DT)





Current Status

- >95% of infants in the United States are screened for hearing loss prior to hospital discharge
- 41 states mandate NHS

60% of infants referred from newborn screening may be lost to follow-up (CDC)



Service Delivery Challenges

- Communication between stakeholders
- Stakeholder knowledge of best practice
- Timeliness of service delivery
- Availability of professionals with appropriate expertise and equipment

***Be Aware of Critical Components
along the EHDI Continuum***



Case Example: Alex (Screening to Diagnostics)

- Full term, no complications; family hx of hearing loss (deaf parents)
 - Failed inpatient NHS both ears
 - Failed 3 outpatient OAE screenings over a three month period
 - Diagnostic test completed at 4 months of age
 - Click ABR revealed severe hearing loss bilaterally
 - Equipment did not have capability to do tone burst



Problems (Screening to Diagnostics)

- Problems:
 - Delayed diagnosis
 - Referral to diagnostic test not timely
 - Too many screening attempts
 - Insufficient testing completed to fit hearing aids
 - No frequency specific threshold data
 - Additional ABR required before amplification can be fit
 - Further delays process

Infant Test Battery

Joint Committee on Infant Hearing Year 2007 Position Statement

- Case history
- Physiologic measures
 - Auditory Brainstem Response (ABR)
 - Click
 - Frequency-specific
 - Bone conduction
 - Otoacoustic Emissions (OAE)
 - Middle ear measures
 - Tympanogram using a high frequency probe tone
- Observation of behavioral response to sound





Infant Diagnostic Testing Components

- Test battery components
 - Position statements, state guidelines
- Equipment needed
- Counseling/Parent Education
 - Resources
 - Parent organizations
- Referrals following identification of hearing loss (medical, early intervention)
- Reporting requirements (Department of Health)



Equipment Required

Practice Questions:

Does the practice have:

- OAE equipment?
- Immittance bridge with a high frequency probe tone?
- ABR unit with click, tone burst, AND bone conduction?

If the answer is no to ANY of the above, the practice is not equipped to do comprehensive infant diagnostic testing



Case Example: Alex (Diagnostics to Amplification)

- Diagnosis made at 4 months of age (early December)
 - Medical clearance obtained
 - Impressions taken; earmolds ordered
 - Loaner hearing aids obtained
 - Next appointment scheduled for mid-January due to Holidays and scheduling problems



Problems (Diagnostics to Amplification)

- Delay in amplification fitting
 - Earmolds outgrown before fit
 - Extended time without auditory stimulation
- Insufficient data to appropriately program hearing aids
 - Only click ABR obtained



Case Example: Alex (Amplification)

- Loaner hearing aids programmed after the Holidays
 - No real ear equipment available
 - First fit manufacturer settings used
 - Feedback
 - Turned down settings “somewhat” to reduce feedback and due to age



Problems (Amplification)

- Could not verify hearing aid settings for:
 - Audibility of speech
 - Soft, average, and loud
 - Maximum real ear hearing aid output
- First fit settings vary significantly for the same loss across manufacturers

Note: subsequent testing revealed hearing aids were significantly underfit

Amplification Process

American Academy of Audiology (2003) Pediatric Amplification Protocol

- Selection
 - Technology/Earmold characteristics
 - Individual Real-ear-to-coupler-difference (RECD)
- Verification
 - Real-ear or simulated measures (soft/med/loud)
- Caregiver hearing instrument orientation
- Validation
 - Benefits/limitations, measures/te
- Follow-up and Referral





Equipment Needed

Practice Questions:

Does the practice have:

- A real ear analyzer?
 - Does it have RECD capability
 - Is there an option for a speech signal (preferable)?
- Hearing instrument software and supplies designed for pediatrics?
- A loaner hearing aid program/access to loaner hearing aids?



Case Example: Alex (Early Intervention)

- A referral to the early intervention system was made at the time of diagnosis
 - Due to the holidays services began in January
 - The speech pathologist had no previous experience with an infant with hearing loss
 - Developmental therapist for the hearing impaired began to visit the home monthly



Solution

- Education!
 - Continuing professional education
 - Initial professional education



Problems (Early Intervention)

- SLP has lack of expertise in working with hearing loss impacting familiarity with:
 - Resources
 - Parent education needs
 - Other services needed
 - Amplification
- DTH providing infrequent visits



Early Intervention Considerations

- Do providers collaborate to know if problems are occurring?
 - *responsive to concerns, respect for opinions*
- Do providers have an understanding of:
 - Potential problems that can impact early intervention
 - *consistency of amplification, ear mold problems, effectiveness of communication methodology*
 - The impact of OME for children with sensorineural hearing loss?
 - The complexities of early intervention and audiological management for infants and toddlers with medical syndromes and auditory neuropathy/auditory dys-synchrony?



Early Intervention Considerations

- Do providers:
 - Have the training and experience required to work with infants and toddlers with hearing loss?
 - Utilize family-centered practices?
 - Have familiarity with all areas of child development?
 - Utilize intervention strategies appropriate for infants and toddlers rather than preschool strategies downsized?

Early Intervention Considerations

- Do providers:
 - Monitor progress over time?
 - Assess in all areas of child development and/or collaborate with others to know this information?
 - Use assessment to guide intervention?
 - Use assessment to determine if a change in intervention is warranted?





Questions to Consider

- Do I work in partnership with other members of the early intervention team?
- Do I value the expertise of other members of the team?
- Do I resolve professional differences in a way that does not put the parents in the middle of a professional disagreement?



Guidelines and Position Statements (Diagnostics and Amplification)

- *Joint Committee on Infant Hearing Year 2007 Position Statement*
- *State EHDI Guidelines*
- *American Speech-Language-Hearing Association (2004). Guidelines for the audiologic assessment of children birth to 5 years of age*
- *American Academy of Audiology Pediatric Amplification Protocol (2003)*
- *American Speech-Language-Hearing Association (1992). Sedation and topical anesthetics in audiology and speech-language pathology. *Asha*, 34 (March Suppl. 7), 41-42.*
- *American College of Medical Genetics (2002): Genetics evaluation guidelines for the etiologic diagnosis of congenital hearing loss. *Genetics in medicine*, 4 (3), 162-171.*



Best Practice and Guidelines (Early Intervention)

- Alexander Graham Bell Early Intervention Best Practice Model
- The National Agenda: Moving Forward on Achieving Educational Equality for Deaf and Hard of Hearing Students (April 2005) Goal One: Early Identification and Intervention
- Report and Recommendations of the 2004 National Consensus Conference on Effective Educational and Health Care Intervention for Infants and Young Children with Hearing Loss



A Shifting Paradigm

“The nexus of several factors – early identification, early intervention, greater parental awareness, and improved technology - has led to a growing paradigm shift in the habilitation and education of children with hearing loss. Never before in history have children with significant hearing loss had the potential for such communicative and academic success.” (Houston, T., 2003)



Educational Challenges

Knowledge and Skills in working with Infants and Young Children with Hearing Loss

- Shortage of professionals with specialized expertise
- Few University programs providing specialized training
- Few University programs incorporate interdisciplinary teaming



Teacher Preparation in the US

- **Seventy** teacher preparation programs in U.S. with a specialty in deaf/hoh.
- ~**Eight** of which report a specialization in auditory based education.
- Thus, there's a critical shortage of professionals who have the necessary training to facilitate spoken language.
- For many children, especially in rural areas, education and intervention options are often limited.



Teacher Retention – 788 Graduates

- Almost one-tenth of new teachers nationwide leave the profession within the 1st year.
 - Of the 788 graduates, 78 will leave (710 left).
- One-fifth of new teachers nationwide leave the profession within 3 years.
 - Of the 710 still teaching, 142 will leave (568 left).
- One-third of new teachers nationwide leave the profession within 5 years.
 - Of the 568 teachers, 187 leave the profession.
- After five years, less than half still teaching (381).
 - (Source: S. Winston, 2006; Gallaudet Leadership Institute)



Lack of Retention

- Lack of family-centered training
- Meeting the needs of infant/toddler population
- Disconnect between education and practice
 - Self-contained vs. itinerant and/or resource teaching
- Multicultural & diversity needs of families
- Multiple disabilities/varying learning needs of the children
- Understanding & integrating current hearing technology
- Disconnect between “teaching speech” vs. facilitating language through listening/audition
- Lack of confidence with sign language
- Need for ongoing staff development/lifelong learning/mentoring



Speech-Language Pathologists

- Research has shown that practicing speech-language pathologists in the public schools have rated their pre-professional training in the area of childhood hearing loss being “less than adequate” (Moseley et. al., 1994).
- Watson & Martin (1999) surveyed more than 200 SLPs employed in public school settings in four states, examining: nature & management of hearing loss in children, cochlear implants & educational needs of children with cochlear implants.
 - Vast majority considered their training inadequate.



Speech-Language Pathologists

- Rowan, et. al. (2005) examined competencies of practicing SLPs in the public schools in Ohio. Results indicate “both hearing impairments and fluency were identified as major areas of training deficiency.”
- Future: increasing caseloads with children with hearing loss and those using hearing technology & cochlear implants.
 - Greater need for some specialization at the preservice level & opportunities for lifelong learning



Audiologists

- Severe shortage of pediatric audiologists, often mentioned as having significant impact on the loss to follow-up by EHDI programs, Part C coordinators
- Critical need for educational audiologists; expectations increasing within educational programs
- Future: shifting definition of rehabilitation, making pediatrics more attractive and financially viable



Building the *Village*: Interdisciplinary Team Services

- Families – with the parents in the *driver's seat!*
- Among professionals:
 - *fostering a an understanding and appreciation of unique perspectives, knowledge, skills, values and purposes of each of the professions represented on the team;*
 - *ability to listen, to trust, to be open, and to communicate clearly and effectively, and a willingness to give feedback, & to share power and expertise.* (DeGraw, et. al., 1996)



Utah State University

Sound Beginnings of Cache Valley: A Model Program (www.soundbeginnings.usu.edu)

- Interdisciplinary emphasis to train:
 - Audiologists
 - Speech-Language Pathologists
 - Educators of the Deaf

Innovative auditory learning program, serving children from birth through five years with hearing loss who are acquiring spoken language



Auditory Learning Emphasis

- Two year programs
 - Emphasis in SLP & AUD
 - New Master's Program in development for educators
- Additional courses in Auditory Learning & Spoken Language
 - *Facilitating Auditory Learning & Spoken Language, Teaching Speech to Children with Hearing Loss, Pediatric Audiology, Language & Emergent Literacy in Children with Hearing, Working with Families & Teams, Children with Multiple Disabilities, Cochlear Implantation*
- Practicum experience



Philosophy

- *Sound Beginnings* recognizes that each infant and family is unique, and parents are their child's primary teachers. As such, family-centered services are guided by parent needs and choices. An interdisciplinary team working in a coordinated effort supports the family by providing timely, comprehensive, and effective services.



Service Coordination

- For each child:
 - Private Audiologists
 - Cochlear Implant Program
 - Local Part C Programs
 - Public Schools
 - Physicians & Primary Care Providers
 - OT/PT Services
 - Other specialists



Clinical Service Components

Sound Beginnings offers a full range of services:

- Audiological assessment
- Amplification & cochlear implant mapping
- Speech-language assessment & individualized pull-out therapy
- Parent Participation & Training Sessions
- Auditory-Verbal Therapy
- Auditory-Oral Education

Educational Service Components

- Parent-infant program
 - Home-based
- Toddler group
 - Twice per week
- Preschool
 - Five days per week
- Parent seminars
 - Monthly





Educational Service Components

- Practicum Site for Graduate Programs
- Center of Excellence/Model Program to be replicated in other area & at other universities
- University – provides a range of resources
 - Lab School on campus (music, art, library, PE)
 - College of Education & Human Services – continuous improvement model



Impact

- Providing a coordinated, interdisciplinary auditory learning approach for children with hearing loss and their families who reside mostly in northern Utah.
- If we can increase each child's ***auditory capacity***, we will improve their ***auditory performance***.

Case Example: C-K

Coordinated, comprehensive & effective care



- Age: 4 yrs., 1 month
- Hearing Loss: Severe
- Amplification: HAs
- Language Development:
 - See the VIDEO!

C-K



Filmed: July 2007 Age at Filming: 3 yrs. 6 mons.

C-K



Filmed: February 2008

Age at Filming: 4 yrs., 1 month



WEBSITES

- Alexander Graham Bell Association for the Deaf and Hard of Hearing www.agbell.org
- Oral Deaf Education www.oraldeafed.org
- Deafness Research Foundation www.drf.org
- Beginnings for Parents of Children Who are Deaf or Hard of Hearing www.ncbegin.org
- National Center for Hearing Assessment and Management (NCHAM) www.infanthearing.org
- National Institute on Deafness and Other Communication Disorders www.nidcd.nih.gov
- My Baby's Hearing www.babyhearing.org
- Raising Deaf Kids www.raisingdeafkids.org
- Sound Beginnings www.soundbeginnings.usu.edu



Bibliography

DeGraw, C., Fagan, M., Parrott, M., & Miller, S. (1996). Interdisciplinary education and training of professionals caring for persons with disabilities: Current approaches and implications for a changing health care system. Executive Summary. US Department of Health and Human Services.