Resources for Addressing Hearing Differences in Childhood

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Learning Objectives

- Participants will learn key issues to address when serving children with hearing differences.
- Participants will learn local, state, and national resources for serving children and families.
- Participants will have the opportunity to network so as to increase collaboration with providers across the state.
Effective Case Management with Individuals who are Deaf or Hard of Hearing

- Sets a solid communication foundation respecting the rights and needs of the individual with hearing loss
- Empowers the individual and his or her family members with education
- Respects the decisions made
- Encourages self-advocacy
- Recognizes societal barriers and works to reduce them
- Involves self-awareness on the part of the case manager or service coordinator regarding his or her biases, privileges, and power differentials
- Happens from a strengths-based perspective
System of Care Philosophy as Applied to Individuals who are Deaf or Hard of Hearing and their Family Members

**Core Values**
- Community-based
- Family-driven & Youth-guided
- Culturally & Linguistically Competent

**Guiding Principles**
- Comprehensive
- Individualized
- Provided in the least restrictive, appropriate setting
- Coordinated at both system and service delivery levels
- Involve family members and youth as full partners
- Emphasize early identification and intervention
How Important is Hearing Really?

- Experiential Activity with Levels of Hearing Loss
- How could different levels of hearing loss affect your work in a community setting?
- How could the worldview of a person with hearing loss be different or similar?
Early Hearing Detection and Intervention (EHDI)

Resources and Referrals

- Commission for Children with Special Health Care Needs EHDI
  - “UNHS Hospitals List”
  - “Audiology Resource List”
- Lexington Speech and Hearing Center
  - http://www.lhscky.org/
- Heuser Hearing Institute and Language Academy
- Early Childhood Mental Health Specialists
- Hands & Voices
  - www.handsandvoices.org
  - Guide By Your Side
- Kentucky School for the Deaf Statewide Family Support Center
  - http://www.ksd.k12.ky.us/SFSC/a%20sfsc%20home.htm
  - Newsletter
  - Family Learning Vacation

Tips for Case Managers

- In FY2010, 99% of infants born in hospitals were screened. 7,164 were at risk for hearing loss and 40% were lost to follow up in an outpatient setting
- Families with a newly diagnosed infant often go through the stages of grief and struggle with where to turn for help – and where to get objective answers and support
- If the child is involved in First Steps, supplement with some of the resources we are discussing today
- Sometimes the most important resource is another parent of a child who is Deaf or Hard of Hearing
Resources Related to Audiology and Medical Needs

Referral Options

- Commission for Children with Special Health Care Needs (CCSHN)
- Heuser Hearing Institute
  - [http://thehearinginstitute.org/](http://thehearinginstitute.org/)
- University of Louisville Audiology
  - [http://louisville.edu/medschool/audiology/clinical-services.html](http://louisville.edu/medschool/audiology/clinical-services.html)
- KY Academy of Audiology
  - [http://kyaudiology.org/](http://kyaudiology.org/)
- KY Speech Language Hearing Association
  - [http://www.ksha.info/](http://www.ksha.info/)

Tips for Case Management

- Age of Hearing Loss can impact a person’s preferred mode of communication
- Individuals with congenital hearing loss often have a different perspective and path than those with later hearing loss
- If a person has multiple medical problems, addressing hearing loss may be set at a lower priority, but it WILL affect how all info is received and processed
- Individuals and families are rarely presented with a range of choices or options; seeking objective advice and multiple opinions can be a vital role for the case manager
- Adults facing hearing loss may wait 5-7 years before getting help!
Paying for Hearing Aids and Technology

- Medicaid and most insurances will cover hearing aids for children.
- Insurance companies may cover Cochlear Implants for children.
Research indicates that the single most important factor in predicting successful outcomes of newly identified deaf and hard of hearing babies in early intervention is the active participation of their parents.

Yoshinaga-Itano, Coulter & Thomson, 2000
Hands & Voices: Mission Statement

Hands & Voices is dedicated to supporting families with children who are Deaf or Hard of Hearing without bias around communication modes or methodology.

We’re a parent-driven, non-profit organization providing families and the professionals who serve them with the resources, networks, and information they need to improve communication access, social and educational outcomes for their children.

Our outreach activities, trainings, parent/professional collaboration, and advocacy efforts are focused on enabling children who are deaf or hard of hearing to reach their highest potential.
Hands & Voices: What Makes Us Tick

- We are a parent-driven, parent/professional collaborative group that supports families without bias about communication modes and methods.

- We believe that there is no one communication choice that will work for all children who are deaf or hard of hearing. We think families need access to good information that’s free from a sponsoring agenda or ideology.

- We believe that “What works for your child is what makes the choice right.” ©

- We get meaningfully involved in early hearing detection and intervention programs, educational advocacy, and other systems to improve them from an end-user perspective.

- We exist to help our children/students reach their highest potential.

- We believe our children have a fundamental human right to communication, regardless of their mode or method of communication.

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The need and right to communicate is the most fundamental of human rights. To deny it is to harm the human spirit; to foster communication is to reveal all the possibilities of life.

Lawrence Siegel, J.D., Director National Deaf Education Project, 2000
Family Work Must Focus on Effective Communication
Culturally Affirmative and Linguistically Competent Care

- Recognizes that each family is different and uses individualized approaches
- Knows that, in Deaf and Hard of Hearing Services, communication choice and language development have important implications for child development and social / emotional health
Meeting Individualized Communication Needs: Possible Modes of Communication

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<th>English/Oral</th>
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Basics of Teaming with A Sign Language Interpreter

- Have the consumer set up the room as s/he desires
- Generally, the interpreter sits next to and slightly behind the speaker in a 1:1 situation
- Interpreting is generally simultaneous; Interpreters will make different choices to make sure the message is clear
- Go at your regular pace; the interpreter will stop you if necessary
- Avoid use of technical jargon and acronyms
- Provide copies of agenda and written materials before beginning if possible
- **Everything** said in the room will be interpreted
Working with an Interpreter (Continued)

- Conduct a **pre- and post-session** with the interpreter to inform and debrief
- Scheduling interpreters at least a week before meetings is desired
- Use the same interpreter(s) throughout treatment for consistency
- Consider the interpreter the language and culture expert on your team
- Maintain eye contact with the consumer and speak directly to him/her
- In Kentucky, law requires that paid interpreters be **licensed and certified**
- Use family members only with extreme caution and only adjunctive to professional interpreters
- Consider the possibility of vision issues – be aware of lighting, clothing, placement of signs, etc.
- Some services can be reimbursed through the Department
Resources for Obtaining an Interpreter

Resources and Referral Options

- “Guidelines for Working with and ASL Interpreter in a Mental Health Setting”
- KCDHH Access Center
- KY Board of Interpreters Directory of Licensed Interpreters
  - [www.kbi.ky.gov](http://www.kbi.ky.gov)

Tips for Case Managers

- There are pros and cons to using an interpreter referral agency involving convenience, cost, match, and quality
- Work pro-actively with your supervisor to plan for the need
- Know your agency’s policies and guidelines
- Get to know interpreters and develop professional rapport
- Be flexible in scheduling, especially depending on your location
Resources for Paying for An Interpreter / Addressing Cost

**Resources**
- “124 - Enhanced Access Interpreter Reimbursement for CMHC’s”
- Interpreter Payment for AA Meetings
- “DOJ Tax Incentives for Businesses”
- KY ADA Coordinator, Norb Ryan
- Managed Care Organizations (MCOs)???

**Tips for Case Managers**
- Any agency receiving federal funding is under obligation by the ADA to provide “reasonable accommodations”
- The amendments to the ADA and the KY Civil Rights Act provide further mandates
- Working WITH a provider is generally more fruitful than threatening ADA
- A person who signs is NOT the same as an interpreter!
- Try to keep one role at a time – a case manager should not also be the interpreter for a consumer
- You can set the tone for the language access provided to a consumer in a specific setting, in your agency, and in the community
- Be the “change agent” you want to see in your sphere of influence!
Qualified Interpreters Provide ENTRY Into Services….

- This Does Not Always Translate into EQUAL ACCESS to services

- YOU, as the service coordinator, case manager, and advocate, have an obligation to ensure that the Deaf individual is receiving effective treatment!

- Some of your most important work will likely be advocating for language access.
Sometimes an Interpreter Isn’t Enough!

- The presence of an interpreter does NOT guarantee that everyone is on equal ground or has shared understanding
- Use of Deaf Interpreters / Certified Deaf Interpreters
- Necessity of Visuals
- Conveying Key Concepts through gesture, drawing, role play, etc.
- “Talk” Therapy not always effective
Considering the Needs of Persons who are Highly Visually Oriented

- Need for Context
- Importance of Body Language and Facial Expressions
- Eye Contact
- Direct Communication (vs. Incidental Learning)
- Safety Concerns
- Must meet their communication needs
- Behavior as communication
- Anything provided orally to a hearing patient must be provided visually to a Deaf or Hard of Hearing patient
A Note on Dysfluency

- Deaf individuals may have language deficits due to late and inadequate exposure to American Sign Language.
- Other factors may include organicity related to etiology, developmental disability, or, possibly, mental illness.
- Must differentiate between dysfluency related to thought disorder and dysfluency related to language deprivation.
- Individuals isolated from Deaf peers may also display “odd” signing or non-traditional sign symptoms.
Most people are not seeking treatment for hearing loss.

BUT

hearing loss must be considered in treatment planning.
Challenges Children and Families Face

**Home**
- Approximately 92% of deaf children have hearing parents
- Only 15% of parents develop the sign language communication skills necessary to have meaningful communication
- Often, the mother is appointed as “the communicator”
- Context for events and incidental learning
- Moral education is limited when parents can’t “pass the salt”
- Children often don’t learn coping skills and see “acting out” as their only hope for getting points across

**School**
- Parents may not have choice in the type of communication the school offers
- Limited access to sign language and communication classes
- Isolation of children in mainstreamed schools reduces number of language and role models
- Limited financial and human resources make it difficult to match IEP needs with actual services
- KY Interpreter Licensure has lower standards for educational interpreters serving those who need language models the most
- Limited number of Deaf Educators who are Deaf themselves
Considerations when working with Deaf and HH person and/or family member.

- Understand that **incidental learning** is inhibited for deaf and hard of hearing individuals.
- Language – ASL, Signed English, Oral, Idiosyncratic signs.....What are their accessibility needs?
- Etiology (and age) of their hearing loss. This will impact language and social development, understanding of mental health needs, independent living skills, self-care.
- Education – mainstream, deaf school, oral schools, interpreters
- Social participation...do they have supports?
- Family communication and perception
- Approximately 90% of Deaf children and Adults have hearing parents.
**Elementary and Middle School Resources**

**Resources**
- Kentucky School for the Deaf Outreach Specialists
  - “Spec Ed Coops By County 9-10”
  - “Interpreter Checklist for IEP Meetings”
  - “Relationship of Hearing Loss to Listening and Learning Needs”
- Mini Deaf Olympics
- Lions Club Camp
- Trooper Island – KCDHH
- Hands Alive!
- Xtreme Xperience
- Deaf Teen Quest

**Tips for Case Managers**
- Children in mainstream programs are often isolated from Deaf peers
- “Least Restrictive Environment” for a child who is Deaf or Hard of Hearing is where they have communication access
- IEP Plans and realities can be vastly different for Deaf students. Advocacy from a service coordinator can be key
- Creating opportunities to have Deaf or Hard of Hearing peers and role models builds a buffer or protective factor against higher risk for physical, sexual and substance abuse
- “…and Hard of Hearing” dangers
- Only 25% of kids identified as SED who were Deaf or Hard of Hearing received IMPACT services. There are no DHHS specialists who are IMPACT providers
Transition Age Resources

Resources
- “Laurent Clerc Transition Skills Guidelines”
- Office for Vocational Rehabilitation Office of Deaf Services
  - “Vocational Rehabilitation Deaf Services Guide”
  - “Rehabilitation Counselors for the Deaf map”
- Student-Directed IEP’s
- PepNet: Advancing Educational Opportunities for People who are Deaf or Hard of Hearing
  - www.pepnet.org
    - Online Courses
    - iTransition

Tips for Case Managers
- Transition is really a lifelong process. Working with individuals and their families to have increasing levels of independence and self-advocacy skills is key to the individual’s success.
- In some areas, there is still a stigma to having a child who is Deaf or Hard of Hearing resulting in sheltering.
Additional Helpful Resources

Organizations For and By Those with Hearing Differences:

- American Society for Deaf Children
- Hands & Voices
- National Association of the Deaf
- Hearing Loss Association of America
- Alexander Graham Bell Association
Helpful Websites

Information on Hearing and Technology

- My Baby’s Hearing: http://www.babyhearing.org/
- National Center for Hearing Assessment and Management: http://www.infanthearing.org/
- Hear It: http://www.hear-it.org/?page=5508
Websites on Education

- Raising and Educating Deaf Children: [http://raisingandeducatingdeafchildren.org/](http://raisingandeducatingdeafchildren.org/)
Discussion...

What resources do you think will be most helpful?  
What is still lacking?  
How can collaboration help to fill gaps?
Keep in Touch!

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