



Providing Effective Services to Children who are Deaf or Hard of Hearing

System of Care Conference 2014

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Learning Objectives

- Participants will know examples of providing effective communication and how ineffective communication hinders the therapeutic process.
- Participants will learn about barriers to wraparound services that children with hearing differences face.
- Participants will learn resources for serving the population and identify collaborative strategies to pursue in the expansion and redesign of the System of Care

System of Care Philosophy as Applied to Individuals who are Deaf or Hard of Hearing and their Family Members

SOC Values and Principles

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

Relevance to Deaf Community

Values

- Community defined geographically but also by language identity and shared life experience
- Families often lack choices or support
- Youth may not have opportunities to self-advocate
- A wide range of knowledge and resources is needed to effectively serve individuals who are Deaf or Hard of Hearing in a culturally and linguistically competent manner

Guiding Principles

- "Whole Child" focus often missing
- Typical to expect the child to fit the services rather than the other way around
- Definitions of LRE may not lead to the "Most Supportive Environment"
- Current lack of coordination
- Oppression and language barriers often lead to less than full partnerships
- Lack of specialized children's services in KY

What We Face Is...A New Beach

In a community along the coast, everyone was preparing for a pending hurricane. While out driving for some last minute supplies, one resident overheard an interview between a newscaster and a geologist, the latter whose specialty was the impact of storms and climactic change on shorelines and beaches.

The interviewer and his guest were discussing the severity of the pending storm and the current warnings for local residents. They discussed the official notification that the storm would hit the immediate local community. As the driver felt the anxiety of protecting himself, his family, and his property from the storm, the interviewer asked the geologist what he would expect to see tomorrow after the storm. The geologist answered simply, ' A new beach.'

-From Margaret Wheatley in [The Leadership Equation](#)



What Do Individuals who are Deaf or Hard of Hearing Need to Weather the Storms?

- Communication
- Connections
- Community
- Resources



**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

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

Family Work Must Begin with Effective Communication



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

Common Themes

- Deaf/HH children experience a range of difficulties like many others. Loss of a family member, struggling in school, peer pressure. "Growing up".
- Deaf children can be isolated at school. Sometimes they are the only deaf, communication is thru an adult interpreter. Difficult to interact and "hang out" with their peers. After school participation is limited.
- Often come from families who have not established effective communication, support system.
- Incidental learning
- There are families who want to provide support, but there is a lack of resources for the parents as well. (No sign classes for parents to become fluent, receive one perspective (doctors)).



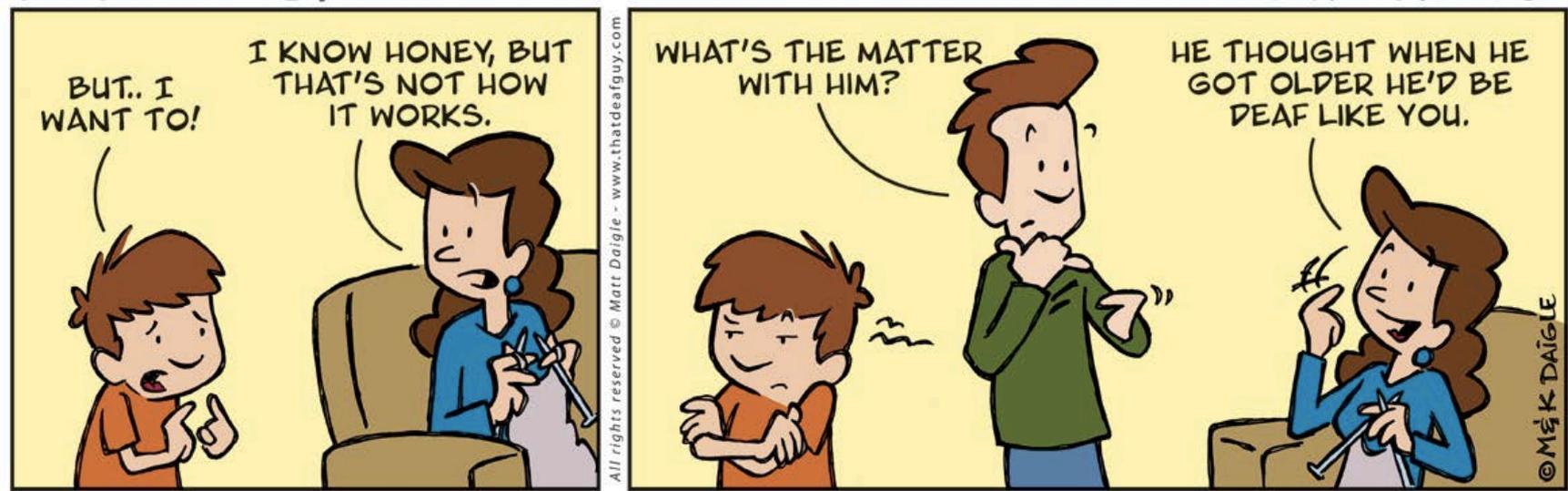
Diagnosis/Misdiagnosis

- Children are often assessed by professionals who have little to no experience.
- Deafness is often assumed to be the source of struggles.
- Many deaf children are identified to “act out a lot”
- Axis II diagnosis often inaccurate. Lack of incidental learning, communication within the family diagnosed as borderline intellectual functioning or DDID.
- Social opportunities are limited for children to spend time with their deaf or hard of hearing peers. Children are spread out the school system. Different perspective of LRE. Lack of exposure to successful adults.

"A Different Center" or Deaf Gain

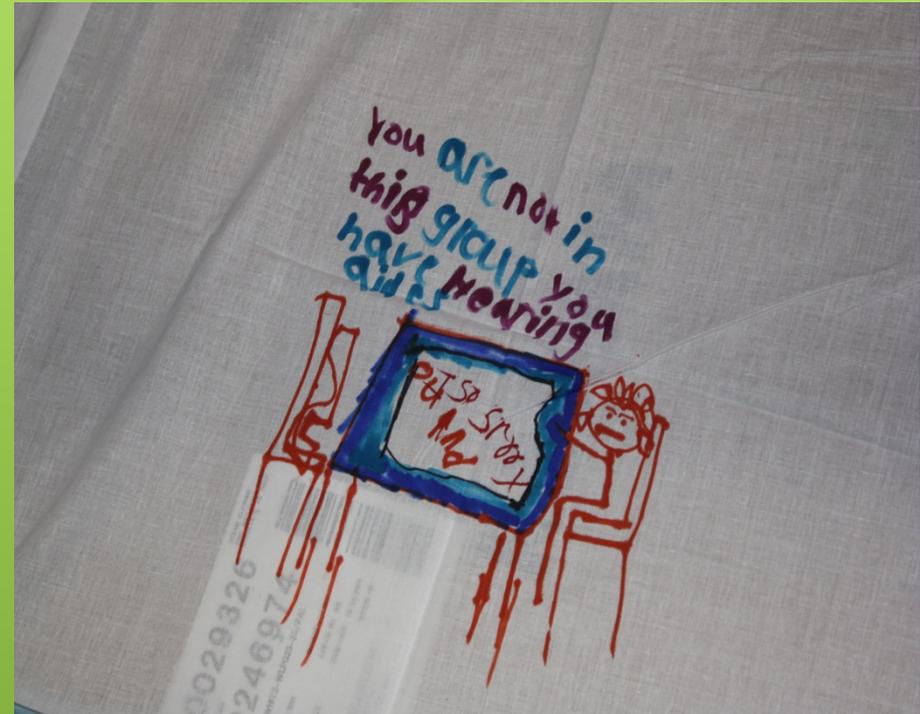
THAT DEAF GUY

BY MATT & KAY DAIGLE



Additional Factors to Consider when Treating Children who are Deaf

- Language Deprivation
 - Age of Identification of Hearing Loss
 - Family Structure and Acceptance of Hearing Loss
- Educational Deprivation
- Fund of Information Deficits due to Incidental Learning challenges
- Safety
- Isolation
- Trauma Histories
- Need to adapt treatment



Evidenced Based Practices



- Adapting “hearing” materials
- Utilize language friendly interventions
 - PCIT
 - Play Therapy / Expressive Therapy
- Always allow extra time
- Role model
- Direct intervention ideal

Barriers to Providing Effective Services: A Therapist's Perspective

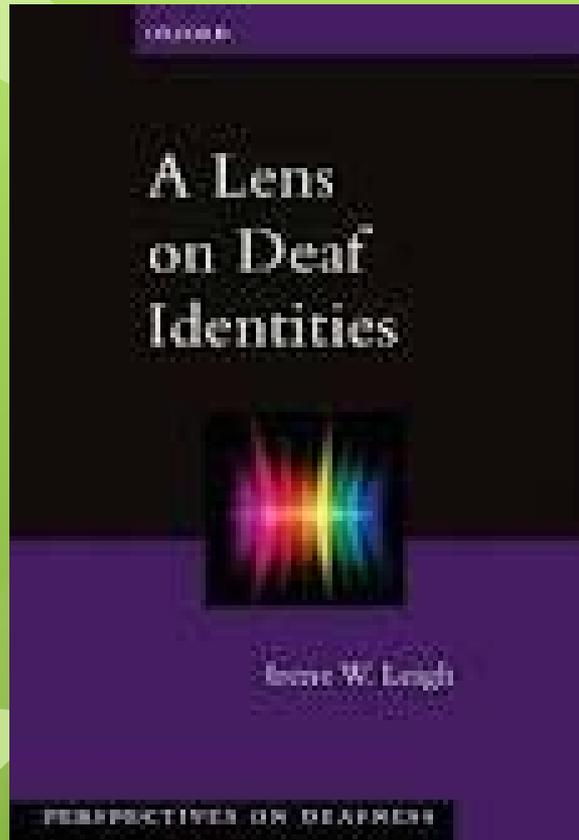
- Lack of structured system to address deaf and hard of hearing needs.
- Interpreters not being provided.
- Staff not being aware of cultural issues.
- Assessments are done by those who may not have any experience or training related to deafness
- Oppressive attitudes and actions.
- Families may not get all of the information up front to make informed decisions.

KY Currently Lacks a Specialized Continuum of Care for Deaf Youth

Services Needed

- Acute Hospitalization
- Crisis Units
- Specialized Therapeutic Foster Care
- Traditional Foster Care
- Group Homes
- Residential Treatment Facilities
- Transitional Living / Independent Living Skills

Identity and Stereotypes



“One of the problems for people who are deaf is that they are in a minority group in society, but probably...have the most heterogeneous needs and range of abilities (which) many writers, parents, professionals, and even the deaf themselves fail to appreciate.”

-Kent &
Smith
(2006)
p. 471

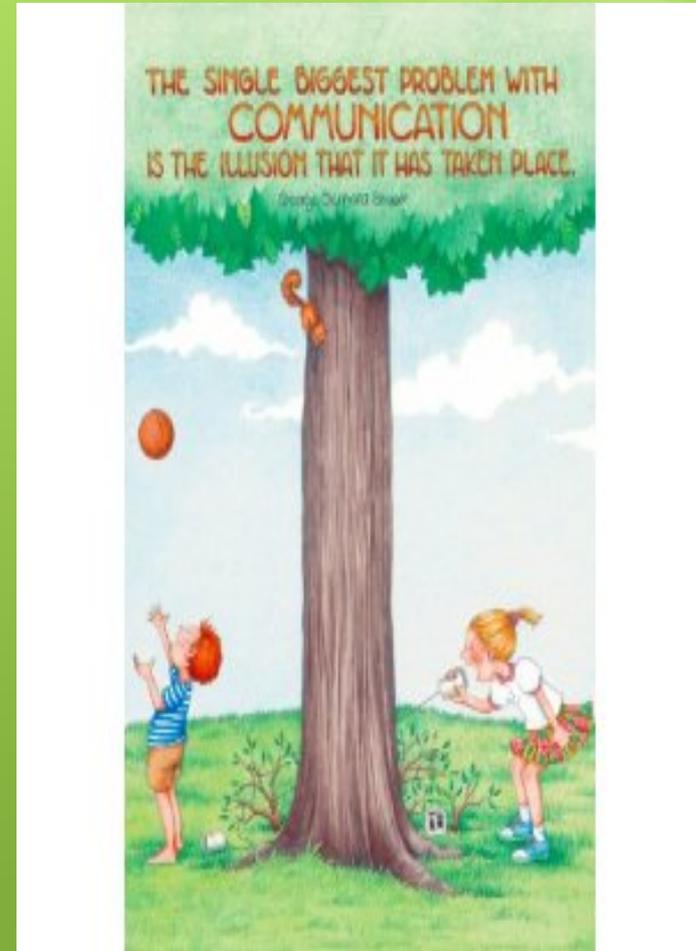
Meeting Individualized Needs



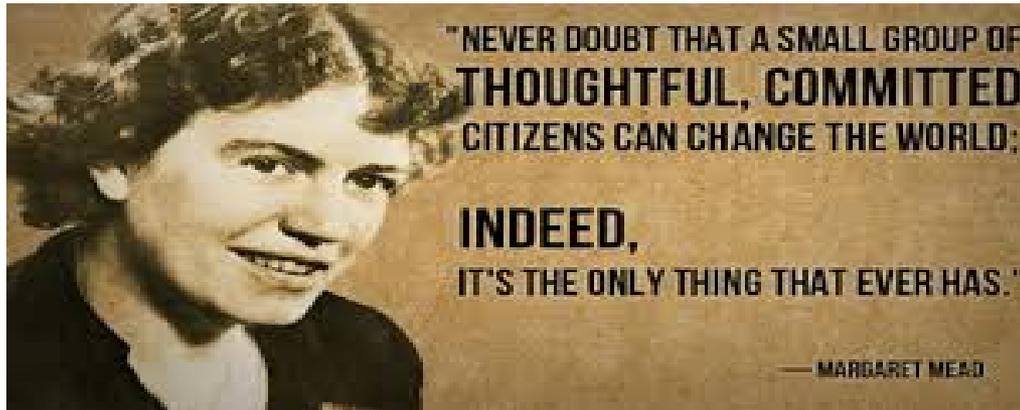
- Children who are Deaf or Hard of Hearing entering child-serving agencies have unique constellations of needs
 - A foundation of effective communication must be established
 - Clinical concerns are often at a critical level
 - Resources – financial, human, and specialized – are more limited
 - Creativity and collaboration are needed to address needs effectively

Having a Qualified Interpreter is a beginning to effective services!

- Every person on the treatment team holds responsibility for ensuring effective communication
- We are seeing more children with Cochlear Implants or hearing aids who do not sign – but DO need accommodations
- Best Practices in Deaf Services calls for direct communication in a person's best language



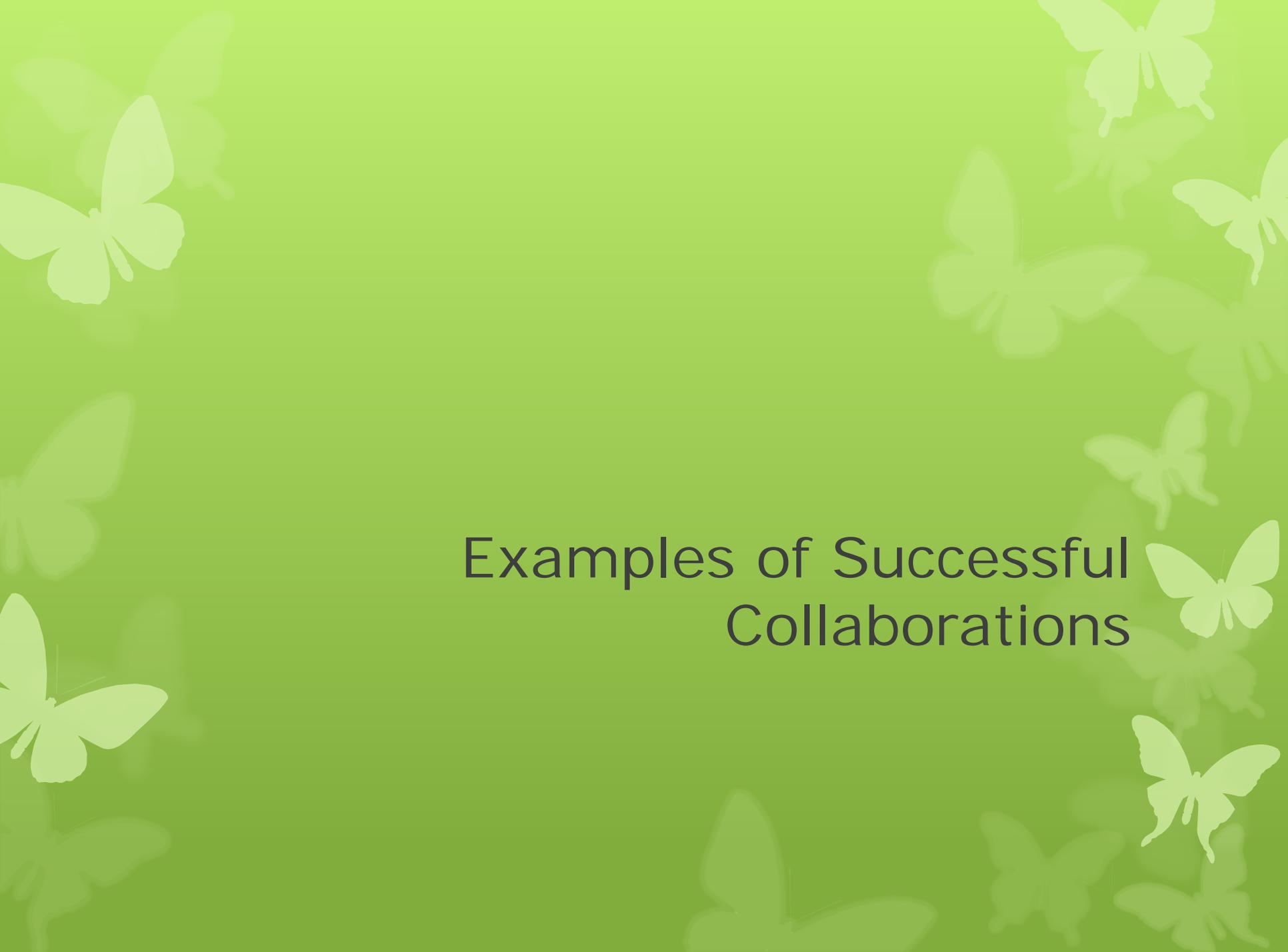
Let Us Dream Together....



- What if we created a network of providers willing to develop expertise statewide?
- What if we worked together to have a specialized acute unit?
- What if we had a cadre of foster parents ready to serve?
- What if we had residential treatment options with culturally and linguistically affirmative services?
- What if your expertise joined ours and we impacted Deaf youth and their families?

Guidance for Creating an Effective SOC for DHH Youth

- National Association of the Deaf Position Statement on Children's Services
 - <http://www.nad.org/issues/health-care/mental-health-services/for-deaf-children>
- National Association of the Deaf Position Statement on Foster Care
 - <http://www.nad.org/issues/health-care/position-statement-quality-foster-care-services-continuum-deaf-children>
- National Child Traumatic Stress Network: Addressing the Trauma Treatment Needs of Children who are Deaf or Hard of Hearing and Hearing Children of Deaf Parents
 - http://www.nctsnet.org/nctsn_assets/pdfs/edu_materials/Trauma_Deaf_Hard-of-Hearing_Children.pdf
- Position Statement on Interpreting in Mental Health
 - <http://www.nad.org/issues/health-care/mental-health-services/position-statement-mental-health-interpreting-services-peo>

The background is a light green gradient with several white butterfly silhouettes scattered across it. The butterflies are of various sizes and orientations, some appearing to fly towards the center. The overall aesthetic is clean and nature-inspired.

Examples of Successful Collaborations

Strategies for Larger Organizations

- Consider having a “point person” to coordinate services for individuals who are Deaf or Hard of Hearing. They can learn the resources and develop rapport with other providers statewide. If you have teams, designate teams to develop expertise or identify local resources.
- Hire or contract with Deaf or sign-fluent staff for consultation and direct services
- Collect data on the number of individuals you serve who are Deaf or Hard of Hearing. Bring it to management team meetings to discuss how to address unmet needs.
- Consider MOAs or MOUs that include blended or braided funding to serve children in multiple state systems.
- Contract with an interpreter coordinating agency or at least 2-3 freelance interpreters. Provide an orientation to your agency and expectations and get to know them.
- Ensure that you have policies and procedures in place for obtaining and paying for accommodations.
- Allow flexibility in scheduling and protocols to meet individualized needs.

Strategies for Smaller Organizations

- Have a designated contact to consult with if a deaf consumer is needing services whether in or outside the agency.
- Be aware of appropriate referrals if your agency cannot meet an individual's needs.
- Have a binder with information on referrals and Deaf-specific resources.
- Consider pooling resources with similar agencies to train Deaf staff
- contact information for interpreters.



Discussion...

How Can We Come Together to Affect Change?

Where Do We Go From Here???

The background features a smooth green gradient that transitions from a lighter shade at the top to a darker shade at the bottom. Scattered across this gradient are numerous white butterfly silhouettes of various sizes and orientations, creating a decorative and naturalistic feel.

Additional Resources

Resources for Obtaining an Interpreter

Resources and Referral Options

- KCDHH Access Center for State Agencies
 - <http://www.kcdhh.ky.gov/oea/referral.html>
- KY Board of Interpreters Directory of Licensed Interpreters
 - www.kbi.ky.gov

Tips

- Direct communication for services is ALWAYS preferable to going through an interpreter.
- 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

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.

Resources Related to Audiology and Medical Needs

Referral Options

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

Tips

- Be sure to address medical needs early!
- 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 advise and multiple opinions can be a vital role for the case manager

Early Hearing Detection and Intervention (EHDI)

Resources and Referrals

- Commission for Children with Special Health Care Needs EHDI
- Lexington Speech and Hearing Center
 - <http://www.lhscopy.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

- 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

Elementary and Middle School Resources

Resources

- Kentucky School for the Deaf Outreach Specialists
- Mini Deaf Olympics
- Lions Club Camp
- Hands Alive!
- Xtreme Xperience
- Deaf Teen Quest

Tips

- 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
 - Rehabilitation Counselors for the Deaf
 - Communication Specialists
- Student-Directed IEP's
- PepNet: Advancing Educational Opportunities for People who are Deaf or Hard of Hearing
 - www.pepnet.org
 - Online Courses
 - iTransition

Tips

- 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

Helpful Websites on Deaf and Hard of Hearing Issues

Deaf

- www.kcdhh.org
- www.nad.org
- www.Gallaudet.edu
- www.aadb.org
- www.forhearingpeopleonline.com

Hard of Hearing

- www.hearingloss.org

Our Contact Information

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