

Building Collaborative Partnerships Across the EHDI Continuum



March 9 - 10, 2009
National EHDI Conference
Addison, Texas

A Shared Responsibility

State and local agencies that are involved in components of an EHDI system should work collaboratively to define their roles, responsibilities, and accountability.

(Joint Committee on Infant Hearing, Yr 2000 Position Statement)

Foundation for this Initiative

Texas State Plan for Students Who Are Deaf or Hard of Hearing

Result # 1

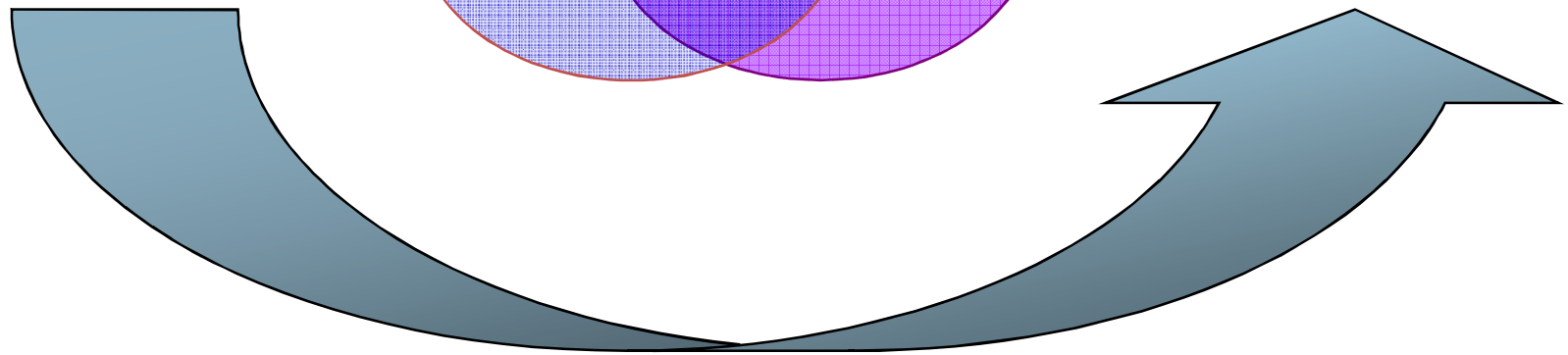
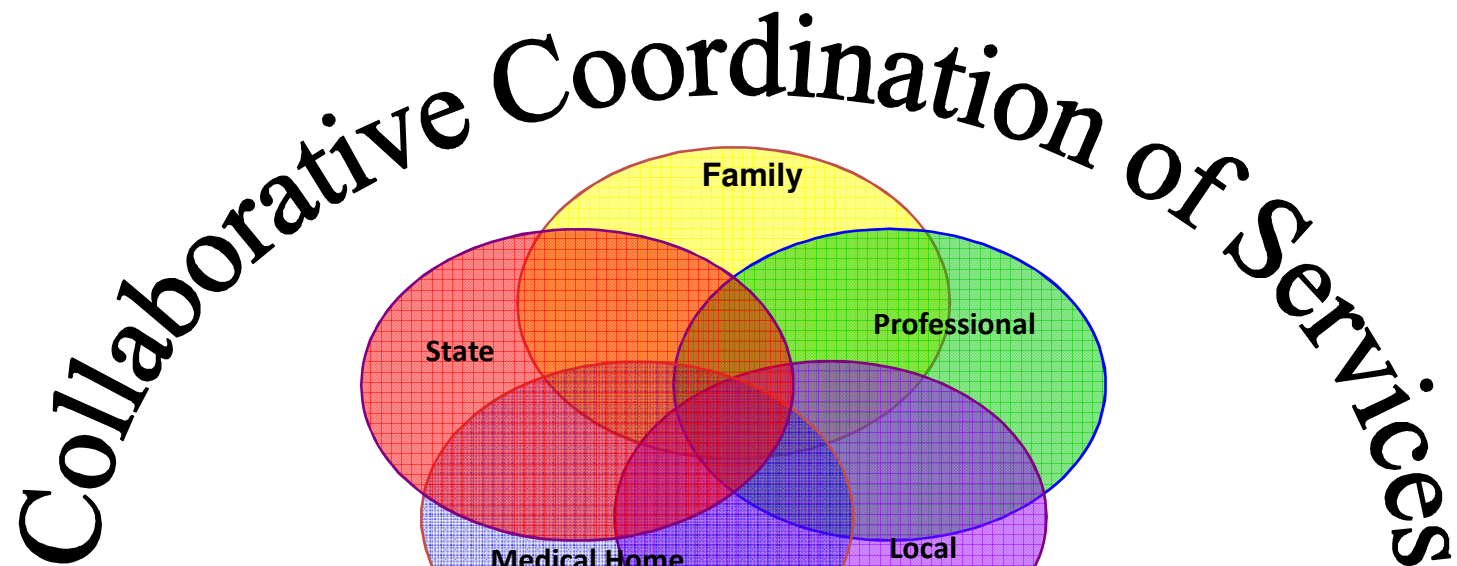
Children who are deaf or hard of hearing, birth through two, are identified and receiving appropriate interventions at the earliest possible age.

Result #2

Preschool students who are deaf or hard of hearing enter kindergarten with developmentally appropriate language/communication skills, cognitive skills and social-emotional abilities.

(<http://ritter.tea.state.tx.us/deaf/deafstateplan.doc>)

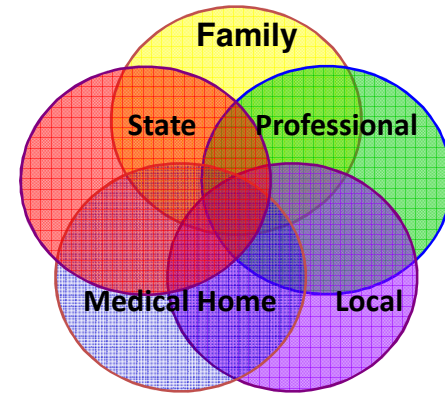
Texas Deaf and Hard of Hearing Leadership Council: Birth to Three



LC's Guiding Principles Resources for Alignment

- ❖ Joint Committee on Infant Hearing YR 2000 Position Statement
- ❖ Center for Disease Control/Natl. Early Hearing Detection and Intervention (EHDI) Goals & Objectives
- ❖ National Agenda for D.HH Students
- ❖ Texas EHDI Practitioners' Referral Protocol (1-3-6)
- ❖ OSEP State Performance Plans for Parts C & B

Texas Deaf & Hard of Hearing Leadership Council: Birth to Three

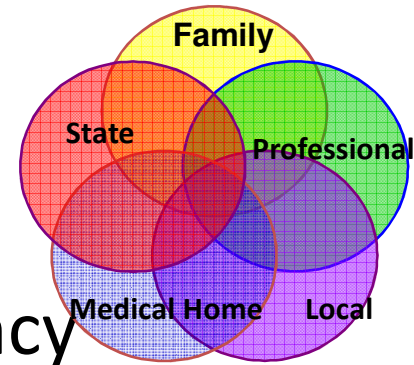


Comprehensive steps would be required to effectively strengthen referral process and mitigate loss to follow-up as data outcomes across agencies were exceptionally poor

Essential for Council Members to thoroughly and honestly examine:

- critical issues that may contribute to poor follow-up rates *across the EHDI Continuum*
- quality improvement issues within the overall EHDI system – introspective and retrospective approaches requested to identify effective improvement activities

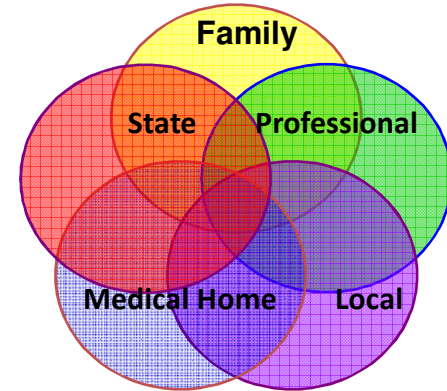
Texas Deaf & Hard of Hearing Leadership Council: Birth to Three



Diverse Leadership relevant interagency and local program decision-makers; community representatives, parents and D/HH representatives

- ❖ State Agencies (TEA/Deaf Education Services, DARS-ECI, DSHS)
- ❖ Early Intervention Educational Programs
- ❖ Parents
- ❖ D.HH Adults
- ❖ Pediatric Providers (medical, audiological, ENT)
- ❖ Personnel Prep
- ❖ Other Agency/Community-based Outreach Programs (ERCOD/TSD, DARS-DHHS, TAIMH, TX H & V)

The Leadership Council's
“charge” is to:



Provide leadership and guidance in the development of comprehensive services for infants and families referred after screening that are coordinated between Infant's Medical Home, families, and related professionals with expertise in hearing loss and state and local agencies responsible for the provision of services to children with hearing loss...

...so that

Early developmental opportunities are maximized, resulting in

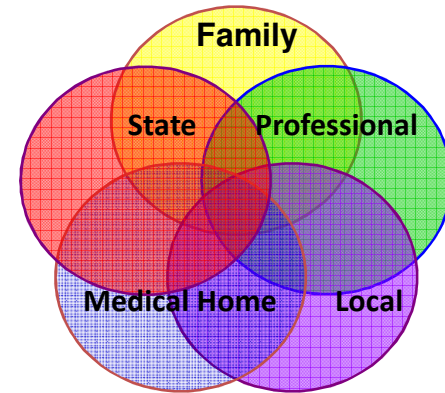
- ❖ improved language outcomes for children
- ❖ improved family outcomes as a result of early hearing detection and intervention process & services

Laying the Groundwork



- ✓ Fall 2006 - Establishment of LC, 4 active subcommittees established
- ✓ Comparison of state agency data, desired outcomes in relation to national EHDI goals/objectives
- ✓ Strategic planning, baseline data collection to include conducting an EHDI Provider and Parent survey to assess the environment, identification of resources and partnerships
- ✓ Subcommittee action plans initiated, resources dedicated to pilot sites, outcome measures in development

TX D.HH Leadership Council Priorities FY 2007 - 2010



Establish a collaborative Statewide Early Hearing Detection and Intervention (EHDI) campaign & related initiatives for professionals and families

- ❖ Standard of Care – eliminate barriers in accessing services
- ❖ Provider Training (medical, audiological, educational, community)

TX D.HH Leadership Council

Priorities FY 2007 - 2010

continued

- ❖ Parent Education/Formal Family Support
- ❖ Educational/Community Outreach and Public Awareness
- ❖ Data Analysis (within and across agencies and programs – DSHS, DARS-ECI, TEA)
- ❖ Determine additional partnerships & funding sources

Referral Protocol & Process



GUIDING PRINCIPLE

Infants referred from Universal Newborn Hearing Screening according to Texas Referral Protocol are referred to local AI/ECI program.

[1-3-6 Texas Medical Home Practitioners' Guide]

Referral Protocol & Process

Background

In Texas the complicated process of ensuring all infants with hearing care needs are identified and receive appropriate early intervention services evolves through the effort several major agencies, health care practitioners and support organizations.

The Texas Department of State Health Services (DSHS) is responsible for managing the hospital Newborn Hearing Screening programs and, through a contractor, maintain the TEHDI data system.

Referral Protocol & Process

Desired Outcome

To increase follow-up for infants that require OP hearing screening, diagnostics, and referrals to ECI/AI services

Actions Needed

Collect data regarding barriers to audiological and educational follow-up

Provide training and education/information to professional personnel and families

Increase public awareness of issues related to infant/childhood hearing loss

Referral Protocol & Process

Activities Completed and Ongoing

- Revising TEHDI referral practice protocols with adaptations for regional variations
- Ensuring easy access and availability of ongoing training for hospital screeners
- Identifying the TEHDI needs for the culturally diverse and continually changing population of Texas

Activities Completed and Ongoing *continued*

- Developing resource materials for physicians and other health care professionals (EHDI Tool Kit)
- Assisting in the support of a statewide parent support group
- Improving methods of collection of follow-up data
- Planning methods to integrate infant health data collection systems
- Enhancing the web-based data system to efficiently allow health care practitioners, audiologists, ECI coordinators and educators to access information needed to serve their clients

Referral Protocol & Process

Future Initiatives

- Disseminate EHDI Tool Kit & provide ongoing technical assistance to promote standard of care reflective of best practices/protocols as outlined in JCIH 2007 Position Statement
- Provide ongoing in-service training to UNHS programs and surrounding EHDI network (Outpatient providers, Medical Home, AuDs, ENTs) across the state
- Increase public awareness of issues related to infant/early childhood hearing loss

Amplification & Monitoring



GUIDING PRINCIPLE

Infants with hearing loss and no medical contraindication begin using amplification when appropriate and agreed upon by the family within one month of confirmation of hearing loss, and receive on-going audio logical monitoring as appropriate.

[JCIH YR 2000 5.3 p. 808]

Amplification & Monitoring

Desired Outcome

Increase families' access to Centers of Excellence for pediatric audiological services emphasizing quality diagnostic audiological assessments, amplification and ongoing monitoring of infants and children regardless of income or geographical barriers

Amplification & Monitoring

Actions Needed

- Increase the number of well trained Pediatric Audiologists throughout the state by providing in-service and training through a multi media approach to metropolitan and rural areas
- Identify a mechanism to cover amplification for those infants and children who do not qualify for Medicaid or CHIP
- Improve reimbursement rates for pediatric audiological services

Amplification & Monitoring

Activities Completed and Ongoing

- Investigate national audiological training resources available for state tailoring
- Assess climate of continuing professional development and complete cost-analysis of delivering training via web, video conference, face-to-face, etc.
- Identify additional partners to support hearing aid funding for non-Medicaid and non-CHIP children
- Review legislation passed in other states related to hearing aid coverage, reimbursement increases, EHDI Phase II Model Legislation (ASHA), etc. to further initiatives as appropriate

Amplification & Monitoring

Future Initiatives

- Disseminate outreach curriculum & provide ongoing technical assistance to promote standard of care reflective of best practices/protocols as outlined in JCIH 2007 Position Statement
- Provide ongoing in-service training with a pediatric focus to audiologists across the state
- Increase public awareness of issues related to infant/early childhood hearing loss

Shared Service Delivery



GUIDING PRINCIPLES

Infants with hearing loss are enrolled and receiving services in a family-centered local AI/ECI program before six months of age.

[JCIH YR 2000 Benchmark 5.1 p. 808]

Families and children receive services from professionals, including AI certified professionals, who are knowledgeable about the communication needs of infants/toddlers with hearing loss.

[JCIH YR 2000 Benchmark 5.2 p. 808]

Shared Service Delivery Committee

Background

In Texas, birth – three early intervention services for children who are deaf and hard of hearing are a shared responsibility.

- The Department of Assistive and Rehabilitative Services Early Childhood Intervention (DARS-ECI) is the state's lead agency for Part C services.
- The Texas Education Agency provides guidance to local education agencies who provide the specialized services specific to children with hearing loss.

Shared Service Delivery Committee

Desired Outcome

Reduce obstacles to referral so that all eligible babies are receiving appropriate services by 6 months of age.

Actions Needed

- Increase understanding of eligibility guidelines for state AI services through clarification of criteria and development of guidance for service providers.
- Increase knowledge of shared service procedures and understanding of importance of early intervention for infants with hearing loss through development of training modules for service providers.

Shared Service Delivery Committee

Activities Completed and Ongoing

AI Eligibility Guidance

- Completed and will be posted on Region 10 Education Service Center website and linked to ECI and TEA websites.
(Target date February 2009.)

Training Modules (in development)

- ECI/AI Roles and Responsibility in Family-Centered Shared Service to Infants and Toddlers Who Are Deaf or Hard of Hearing.
- Impact of Hearing Loss on Children and Families
- Providing Complete Resources to Families

Parent Involvement & Family Support



GUIDING PRINCIPLE

AI/EI programs facilitate parent involvement as a means of improving services and results for Deaf or Hard of Hearing infants and toddlers, including:

- *Knowledge of parental rights.*
- *Effective communication of their child's needs.*
- *Ability to help their child develop and learn.*

[SPP Part C (#4)]

Parent Involvement & Family Support Committee

Desired Outcome #1:

Develop a formal parent organization that provides support specific to families with deaf and hard of hearing children

Desired Outcome #2:

Develop materials (EHDI Parent Kit) to distribute directly to parents in order to encourage and facilitate follow-up screening and enrollment in Early Childhood Intervention (ECI) coupled with DHH educational services

Parent Involvement & Family Support

Activities Completed and Ongoing

Formal Parent Support Opportunities

- Review of current state groups
- Establishment of a state chapter of Hands & Voices
- TX H&V Outreach activities to professionals
- Formal relationships with TX H&V and state agencies
 - Dept. of State Health Services - Family Support Coordinator – EHDI pilot program support
 - Education Service Center Region 10 - Parent Leader Program – EHDI pilot initiative
 - Early Childhood Intervention - outreach to providers
- Exploring establishment of H & V's Guide By Your Side Program

Parent Involvement & Family Support

Activities Completed and Ongoing

continued

EHDI Parent Kit

- Review of parent surveys conducted elsewhere
- Development of Texas EHDI Parent Survey
- Review of parent brochures/materials from other states
- Recommendations for content and delivery method for Parent Kit & related materials. Focus on delivery of information in a tiered manner, based on where the parent/child is in the process (testing, diagnosis, intervention)
- Contribute to design of a statewide EHDI public awareness campaign

Parent Involvement & Family Support

Future Initiatives

- Expansion of Texas Hands & Voices support, based on pilot test feedback
- Explore additional opportunities for collaboration among TX Hands & Voices, state agencies and other parent support groups
- Support the development and distribution of a consistent message throughout the state to parents and professionals about awareness, support and resources

Projected Long Term Outcomes

- ❖ Infants and toddlers with hearing loss will have age-appropriate linguistic (visual and/or auditory), cognitive and social-emotional development as early as possible.
- ❖ Families will report high degree of satisfaction with the EHDI process and services (screening, diagnosis, early intervention, transition to IDEA Part B, as appropriate)

Measure of Effect

Statewide reduction in loss to data, loss to follow-up

Statewide increase in referral/enrollment data across agencies (DSHS, DARS-ECI, TEA)

Statewide improvement in child and family outcome data across agencies (DSHS, DARS-ECI, TEA)

SPP Indicator 3: Percent of infants and toddlers with IFSPs who demonstrate improved:

- Positive social-emotional skills (including social relationships)
- Acquisition and use of knowledge and skills (including early language/communication); and
- Use of appropriate behaviors to meet their needs



Intentional collaboration bound by a shared vision for Texas children and families is beginning to transform our state's EHDI system.

We've taken the "bull by the horns" to improve EHDI outcomes in Texas!



Presenter Information

Karen Clark & Chris Watkins – *Shared Service Delivery Subcommittee*

Lisa Crawford – *Parent Involvement & Family Support Subcommittee*

Karen Ditty – *Amplification & Monitoring Subcommittee*

Eugenia Dunham – *Referral Protocol & Process Subcommittee*

Alicia Favila – *Leadership Council Coordination*