LENDing Support to EHDI Programs

Webcast
Friday, July 21, 2006
1:00 - 3:00pm Eastern

Moderator:

Karl White
Director, National Center for Hearing

AGENDA
LENDing Support to EHDI Programs
July 21, 2006
1:00 - 3:00 p.m. Eastern Time

1:00 Introductions and Purpose of Call
1:10 Judy Gravel: An Update on the Drafting of JCIH 2006
1:25 Reports of LEND Activities to Support EHDI Programs
- Karen Anderson - Florida
- Rich Harward - Utah
- Paul Brueggeman - South Dakota
- Diane Sabo – Pennsylvania
- Jack Roush – North Carolina

2:15 Discussion of Activities in Other States
3:00 Adjourn

An Update on the Drafting of JCIH 2006

Judy Gravel
Center for Childhood Communication
The Children's Hospital of Philadelphia

JCIH 2006 - DRAFT
Position Statement and Guidelines

Definition of Targeted Hearing Loss:

- Identify infants at risk for:
  - **Sensory** HL (congenital/early onset) and **permanent Conductive** HL averaging **of any degree** in one or both ears in **all newborns**; in addition,
  - **Neural** HL in **NICU infants**

JCIH 2006 - DRAFT
Position Statement and Guidelines

Hearing Screening Protocols

- **Separate protocols for Well-Baby Nursery and NICU**
- **Automated-ABR technology recommended as the primary screening tool for use in the NICU**

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Position Statement and Guidelines

Re-Screening Protocols

- **Re-screen both ears** even if only one ear fails initial screening
- **Re-screen NICU readmits in the first month** of life **with conditions associated with hearing loss** (e.g., hyperbilirubinemia requiring exchange transfusion or culture-positive sepsis)

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Position Statement and Guidelines

Audiologic Evaluation

- Audiologists with the experience & expertise and requisite technologies should provide audiologic diagnostic & management services to newborns & young infants

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Position Statement and Guidelines

Audiologic Evaluation

- At least one diagnostic ABR recommended as part of comprehensive audiologic evaluation for children under 3 years with permanent hearing loss

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Position Statement and Guidelines

Audiologic Evaluation

- Timing & number of hearing evaluations for children with risk factors should be individualized depending on the likelihood of a subsequent early acquired hearing loss.

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Position Statement and Guidelines

Follow-up Audiologic Evaluations

- Infants who pass the neonatal hearing screen but have a risk indicator for hearing loss (& regardless of surveillance findings) should have at least one audiologic assessment by 30 months of age
- (eliminated recommendation for audiologic testing every 6 months until age 3 years)

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Position Statement and Guidelines

Amplification

- Infants diagnosed with permanent hearing loss should be fit with amplification within one month of confirmation of HL

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Position Statement and Guidelines

Medical Evaluation

- All families of infants with PHL should be offered genetic consultation
- Every infant with PHL should have at least one examination by an ophthalmologist experienced in evaluating infants

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Position Statement and Guidelines

Risk Indicators

- Organized into a single list
- Focus on early- and late-onset hearing loss

JCIH 2006 – DRAFT: Risk Indicators
Position Statement and Guidelines

- Family/caregiver concern: hearing, speech or language
- Family history of permanent childhood hearing loss
- Cranio-facial disorders, particularly those involving pinna, ear canal, ear tags, pits & temporal bone
- NICU care > 5 days, particularly:
  - Assisted ventilation ≥ 10 days
  - Prolonged exposure to ototoxic medications > 7 days
  - Hyperbilirubinemia requiring exchange transfusion
  - ECMO
- Intra-uterine infections, particularly
  - CMV
  - Herpes
  - Rubella
  - Syphilis
  - toxoplasmosis

JCIH 2006 – DRAFT: Risk Indicators
Position Statement and Guidelines

- Post-natal infections including bacterial meningitis
- Syndromes associated with congenital or progressive HL
- Degenerative disorders assoc. with permanent HL
- Head trauma requiring hospitalization
- Chemotherapy
- (OME x 3 mos. Removed)

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Position Statement and Guidelines

Early Intervention

- All families of infants with any degree of permanent hearing loss in one or both ears should be considered eligible for EI services

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Position Statement and Guidelines

Early Intervention

- Recognized point of entry for early intervention services for infants with a confirmed HL should be linked to EHDI
- Provided by professionals with expertise in HL including
  - educators of the deaf
  - speech-language pathologists

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Position Statement and Guidelines

Early Intervention

- Previous emphasis on "natural environments"
- JCIH will recommend that both home-based and center-based intervention options should be considered appropriate for EI service provision

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Position Statement and Guidelines

Surveillance & Screening in the Medical Home

- All infants should have regular surveillance of developmental milestones, auditory skills, parental concerns, and middle ear status

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Position Statement and Guidelines

Surveillance & Screening in the Medical Home

- Infants who do not pass a Medical Home global screen or if there is a concern regarding hearing or language should be referred for audiologic assessment and speech-language evaluation

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Position Statement and Guidelines

Information Infrastructure

- States develop adequate data management and tracking systems
- Part of an integrated child health information system in order to:
  - monitor the quality of EHDI services
  - provide recommendations for improving systems of care

JCIH 2006 - DRAFT
Position Statement and Guidelines

Information Infrastructure

- A linkage between health & education recommended to determine the outcomes of children with hearing loss at school age
- Information is needed for planning and establishing public health and education policy

Florida's Journey to Attain a System of Quality Pediatric Hearing Evaluation

early steps
Children's Medical Services

Karen Anderson
EHDI Audiology Consultant
Early Steps State Office

newborn screening
Children's Medical Services

HEALTH

So how is Florida doing on accomplishing quality hearing evaluations of infants?

Data as of March, 2006:

- 76.97% of babies passed
- 0.32% passed with risk factors (67)
- 1.5% were referred (318)
- 4.88% were not screened (1,038)
- 16.32% were not reported by hospitals on the metabolic specimen card (3468)
- Audiologists submitted reports of confirmed hearing loss on 0.01%

We needed to have better 'control' of which audiologists see these infants and consistent reporting of results

Why is it important to the state to identify all infant audiologists?

1. Timely follow up to accomplish definitive diagnosis by 3 months is a high priority
2. Parents, hospitals, and physicians must identify audiologists who can follow up appropriately
3. All other disorders identified in newborn screening have a defined path for referral and follow up – the medical community expects and is accepting of having a defined referral path for hearing
4. Process for state approval of audiologists provides credibility and allows for easier tracking of diagnostic and reporting activities

Audiology Centers of Expertise: An idea that didn't work!

- Idea was to identify 20 audiology centers across the state to route UNHS referrals to
- Problems:
  - Needed ACE centers to take **ALL** referrals
  - Payment reimbursement is a patchwork of myriad HMOs, insurance plans, Medicaid, and Medicaid HMOs – **NO place takes all!**
  - Couldn't have a system that wouldn't be inclusive of all children
  - Title V agency and Part C refused to cover children who had payment options or no payment source that the ACE centers wouldn't accept
  - With only 20 in the state, we couldn't expect parents to go to the ACE center that did take their payment plan
  - There was no money to establish sizable contracts to support ACE centers who would be willing to test everyone

The next critical step:

IDENTIFY ALL THE AUDIOLOGISTS COMPETENT AND WILLING TO PERFORM EVALUATIONS ON INFANTS!!!

NEW

Audiologists can now enroll as part of the CMS network in the first non-physician or physician-extender category.

Steps taken on the road to CMS enrollment:

- EHDI Advisory Committee defined the protocol for follow up in June 2004 thus making it possible to describe what an infant audiologist is to do
- Revision of all physician enrollment forms to be more applicable to audiologist requirements
- Development of an Audiology Review Committee (ARC)
- ARC meets monthly to discuss applications and make recommendation to Dr. Chiaro, CMS Medical Director, for approval

CMS enrollment info, etc.

Complete information on how to enroll as a CMS audiologist, reporting forms, etc can be found at:

http://www.doh.state.fl.us/cms/nbscreen-audiologist.html

Requirements for completing CMS audiologist application:

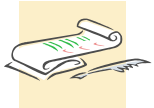
- MINIMUM EQUIPMENT:
  - AER (bone, click, tone burst capability)
  - Impedance bridge with high frequency probe tone capability
  - Screening or diagnostic OAE (DP or transient)
  - Probe microphone system OR an established referral protocol to an audiologist who does infant amplification fitting
  - VRA equipment

  PREFERRED EQUIPMENT TO ALSO HAVE:
  - Diagnostic OAE
  - ASSR

  CAVEAT – IF a clinic lacks all of the required equipment AND is in an area where there are very limited choices for infant audiology services it MAY be possible for EHDI grant funds to be used for minimal support to your infrastructure to allow them to meet the requirements

Requirements for completing CMS audiologist application:

- Audiology license
- Indication of Medicaid status (serving Medicaid patients is NOT required however all patients referred from CMS must be seen)
- Resume' and work history
- 2 professional references



CASELOAD

- Estimate the percent of your caseload that is comprised of children less than 3 years old that you provide diagnostic hearing evaluations to in your current practice setting: _____%
- Estimate the number of children 12 months old or younger you have diagnosed with permanent hearing loss to date: _____
- Estimate the number of children 12 months old or younger you have fit with hearing aid(s): ___
- If you do not fit amplification, where do you refer children for hearing aid fitting (name of audiologist, location)?

NOTE - there is no minimum caseload required

Competency self-assessment

- 1 – 5 ratings, defined competency levels
  - 1 = limited experience; training at an introductory level
  - 2 = Requires input from supervisor or other resource for routine cases
  - 3 = Demonstrates competency independently in most cases; independently seeks resources of additional support when needed
  - 4 = Independently demonstrates competency from routine to complex cases, occasional support needed
  - 5 = Demonstrates competency at all levels of complexity; Mentor level

Competency self-assessment

- Rate competency for different services – test performance and result interpretation

Areas:

  - AER
  - Tympanometry
  - OAE
  - VRA
  - Amplification fitting
- Identify experience in different services
  - Previous experience from start of career
  - Current experience during last year (12 m)

Other information:

- Practice type
- Ability to sedate or referral protocol in place
- Reimbursement options (payers)
- Health status (for ADA accommodations)
- History of disciplinary actions
- Malpractice history

They must sign Agreements and Attestations: TEST PROTOCOL

IF failed one hospital screening test:
  THEN: screening or diagnostic OAE
  OR screening click AER

IF failed two hospital screening tests:
  THEN: diagnostic OAE testing (2000 Hz – 6000 Hz)
  OR air conduction click AER

IF diagnostic OAE results are abnormal or inconclusive **OR** air conduction click AER was not performed

THEN: high frequency tympanometry (600 Hz or 1000 Hz probe tone)

AND: air conduction click AER

IF air conduction click AER is abnormal:
  THEN: bone conduction click AER
  AND: frequency specific tone bursts (500 Hz, 2000 Hz, 4000 Hz)
  AND/OR: Auditory Steady State Response (ASSR)

Agreements and Attestations: TEST PROTOCOL

IF there is a suspicion of auditory dyssynchrony confirm by observing **more than one** of the following:

- AER wave 1 is present with the absence of later waveforms
- Cochlear microphonic is verified in the complete absence of all waveforms
- Middle ear muscle reflex is absent
- AER response indicates moderate hearing loss but there is no observable response to sound stimulation in combination with absent middle ear muscle reflex
- Presence of fluctuating hearing thresholds in the absence of any detectable middle ear abnormalities

IF the child is an audiological candidate for amplification:

THEN: obtain medical clearance for amplification fitting

AND: use probe microphone measures as a part of appropriate hearing aid fitting

Agreements and Attestations: TIMELINES AND REPORTING

A. Every effort shall be made to schedule infants referred from newborn hearing screening so that follow up screening or diagnostic procedures will be completed within 3 weeks (15 work days) following the day of referral.

B. Every effort shall be made to schedule missed appointments within 10 working days of the missed appointment.

C. Any no-show family will be contacted and rescheduled within 3 weeks (15 working days) of the missed appt. Fax the Hearing Results Form to the CMS Newborn Screening Unit, indicating that the family did not show for the appt. so that follow up with the family can occur.

Agreements and Attestations: TIMELINES AND REPORTING

D. Follow up evaluation of well babies with abnormal diagnostic OAE and/or click AER results should occur as soon as possible, preferably within the same appointment or as soon as possible after medical approval for continued evaluation is obtained as necessary.

E. Completion of the diagnostic test battery shall not be delayed beyond 3 months of age for treatment of middle ear effusion. Bone conduction AER procedures should be used as a means to confirm hearing status if a continuing middle ear condition is present.

F. Fax or otherwise transmit the confirmation of hearing status including diagnosis within 2 days of determination to the Children's Medical Services Newborn Screening Program using (a) the Repeat Hearing Screening Form if screening tools were used or (b) the Diagnostic Hearing Evaluation Form if diagnostic tests were used.

Agreements and Attestations: TIMELINES AND REPORTING

G. Children up to age 36 months with apparent late onset or late diagnosed hearing loss shall be referred to the Children's Medical Services Newborn Screening Program via the Diagnostic Hearing Evaluation Form if the child was identified with hearing loss.

H. Refer children under age 36 months who have confirmed hearing loss to the local Early Steps office within 2 days of confirmation. The audiologist shall not wait until complete audiometric information (frequency specific responses) has been obtained to refer the child to Early Steps.

I. Strive to ensure that amplification (loaner or purchased) is fit to children with hearing loss within 30 calendar days of confirmation of hearing loss as appropriate to meet the needs of the child and family.

CAVEAT -

It is recognized that there will be times when the test protocol and reporting requirements must be waived in the interest of the child or family.

There may be some situations in which professional judgment should supersede the practice protocols.

Benefit to the audiologist?

- Recognition of competence
- Part of a recognized network of infant audiologists
- Inclusion on a state-sanctioned list representing an important part of the newborn screening tracking system
- Possible increase in referrals
- Relationship to HELPS providers who can contact parents to assist with their follow through with appointments
- Relationship with Early Steps to provide funding and support for audiology services

Questions / Comments

LEND-EHDI Program Collaboration

Coordination Among Agencies to Improve EDHI Follow-up

Richard Harward
Utah Department of Health

Holly Hyte
Utah School for the Deaf and Blind

0-3 year old children with Permanent Hearing Loss (PHL) Identified by Part C Program and State EHDI Program

(January 1, 2003 through December 31, 2004)

		Part C Program: Identified	Part C Program: Not Identified	
EHDI Program	Identified	81	54	N=135
	Not Identified	62*	??	
		N=143		

* 29 of these children are not in the EHDI data base --- probably because they are out-of-state births or were among the 1.7% who were "missed" for screening in the hospital

Babies identified as PHL by Part C, but as normal hearing in EHDI data-base

	Part C Program: Identified	Part C Program: Not Identified
EHDI Program: Identified	81	54
EHDI Program: Not Identified	62	??

	A. Passed Screening	B. Passed Screening Passed Diagnostic	C. Failed Screening Passed Diagnostic	D Failed Screening No follow-up)
2003	7	1	1	8
2004	7	1	5	3
Total (N=33 of 62)	**14**	**2**	**6**	**11**

A+B=16: Either late onset or false negative screening

C=6: Either late-onset or false negative diagnosis

D=11: Babies with PHL who would have been picked up by EHDI if there were better coordination with Part C

Identified by Part C Program as having PHL, but not present in EHDI data-base

	Part C Program: Identified	Part C Program: Not Identified
EHDI Program: Identified	81	54
EHDI Program: Not Identified	62	??

2003 N=21

2004 N=8

Total: N=29 of 62

Possible Reasons: Child was born outside of Utah

Child missed screening and was not included in EHDI data base (populating the EHDI data-base with Birth Certificate data would solve this)

Identified by EHDI program as having PHL; Not served by Part C Program

	Part C Program: Identified	Part C Program: Not Identified
EHDI Program: Identified	81	54
EHDI Program: Not Identified	62	??

	Total	Unknown to Part C	In Part C data-base as normal hearing
2003	24	21	3
2004	30	28	2
Total	**54**	**49**	**5**

Possible Reasons: Parents well informed about options but chose a different program

Parents not aware of services available from Part C

Question: Hearing status of 5 children classified as normal by Part C but PHL by EHDI program

Next Steps

1. Interview parents of children served by one agency, but not the other to determine
   - ✓ Process by which identification happened
   - ✓ Whether they were adequately informed of services
   - ✓ Factors that prevented timely follow-up
2. Improve system for communication between agencies

Birth Certificate Orders: A Missed Opportunity for Hearing Screening Follow-up

Center for Persons with Disabilities (CPD) at Utah State University
Utah Department of Health (UDOH)

Goal of the Project

- Identify and reduce the number of infants who miss or fail the initial hearing screening.
- Identify children who are or who may become lost to follow-up.

Project Activities

- Design, pilot, and evaluate an “alert” system linking UDOH Vital Records database and UDOH EHDI database through CHARM system
- Identify *lost to follow-up cases* when parents apply for child’s birth certificate

LEND and EDHI

Pennsylvania

Benefits to the State

- Added resources
- Collaboration
- Innovation
- Awareness

Benefits to Trainees

- Awareness
- Collaboration
- Experience