Title: The Ethics of EHDI—What Audiologists Need to Know

Author(s): Les R. Schmeltz, Au.D. 1, Karen Munoz, M.S. 2, Karen Clark, M.A. 3

Affiliation(s): 1 A.T. Still University, NCHAM Technical Assistance Network, 2 Northern Illinois University, NCHAM Technical Assistance Network, 3 UTD/Callier Center for Communication Disorders, NCHAM Technical Assistance Network

Presented by: Les Schmeltz, Karen Munoz, Karen Clark

Abstract: Audiologists are bound by codes of ethics from several professional organizations, including AAA, ASHA and ADA. While ethical boundaries are quite well established for professional activities with older children and adults, the ethics of EHDI are still unfamiliar to many audiologists. Infants present unique requirements for prompt, accurate diagnosis with specialized equipment and techniques. Amplification for infants requires the audiologist to learn new concepts and methods. Counseling parents and families, presenting communication options, dealing with early intervention providers and functioning effectively within the confines of the EHDI system are areas unfamiliar to many audiologists. The objective of this session is to familiarize EHDI stakeholders with practices and procedures that address the unique needs of infants and their families while remaining within the ethical boundaries outlined by organizational codes. The presenters will outline the relevant provisions of the three codes of ethics and then discuss how the codes apply to screening, diagnosis, amplification, counseling and early intervention services provided by audiologists to infants and their families.

Keywords: Ethics, audiologists, practices, EHDI
**Title:** What Professionals Need to Know to Promote Parent Advocacy

**Author(s):** Gerri Hanna, Esq., Senior Director of Advocacy and Policy 1, Barbara Raimondo, Esq., Director of Advocacy 2, Leeanne Seaver, M.A., Executive Director & Director of Educational Advocacy 3

**Affiliation(s):** 1 Alexander Graham Bell Association for the Deaf and Hard of Hearing, 2 American Society for Deaf Children, 3 Hands & Voices National

**Presented by:** Gerri Hanna, Barbara Raimondo, Leeanne Seaver

**Abstract:** Professionals can play a unique role in actively supporting families in their efforts to secure appropriate services for their infants, toddlers and school age children. With EHDI systems in mind, this session will highlight the general principles of the IDEA, focusing on specific sections and selected 2004 Regulations concerning children who are deaf or hard of hearing. Also covered are parent involvement and the protections of law that give parents the right to participate as a team member in decision making; focus on the provisions of a free appropriate education; assessment and evaluation practices; development of the IFSP and IEP; and procedural safeguards. This session will also emphasize the active role that parents can and should take in their child's education.

The provisions of Part C, Infants and Toddlers, and the IDEA will be discussed along with family centered principles and services as well as special considerations that need to be addressed when a child is transitioning from infant-toddler services to Part B services.

The session will explore the challenges and opportunities that are currently being faced in obtaining services and placements for children who are deaf or hard of hearing, such as eligibility issues, natural environments and least restrictive settings, communication-driven programming, and access technology. It will provide examples of efforts that are underway that are making the system more responsive to the needs of children who are deaf and hard of hearing. Participants can submit questions for a closing Q&A, and will go away with three of the most important "tips" that a professional can employ to support families and children who are deaf and hard of hearing.

**Keywords:** Education, Advocacy, Family Support, Early Intervention
Title: Using the Internet to Provide Targeted EHDI Education for Physicians

Author(s): Robert C. Cicco, MD, FAAP, Diane L. Sabo, PhD

Affiliation(s): Pennsylvania Department of Health Infant Hearing Screening Advisory Committee (Dr. Cicco and Dr. Sabo); Pennsylvania Chapter, American Academy of Pediatrics (PA AAP) – (Dr. Cicco); National Center for Hearing Assessment and Management – (Dr. Sabo)

Presented by: Robert Cicco, Diane Sabo

Abstract: Screening rates have risen but losses to follow-up after hospital discharge remain a problem. This is partly attributable to failure to connect with the medical home to assure referral for diagnostic testing, appropriate medical workup, linkage to early intervention, and support and guidance to families. The Pennsylvania Department of Health contracted with PA AAP to undertake an outreach effort targeting physicians known as EPIC-EHDI (Educating Physicians in the Community). EPIC-EHDI provided grand rounds presentations in hospitals and statewide teleconferences, with the goal of increasing the number of babies screened and physicians’ awareness of the importance of follow-up. The effort contributed to a marked increase in the number of infants diagnosed and treated.

Physician outreach has been expanded through an internet-based CME course named Online-EHDI. The course targets physicians with newborns entering their practices that have not passed hearing screening. It consists of four clinical case vignettes that physicians can read and respond to clinical decision-making questions as each case unfolds. Each deals with a different aspect of hearing loss, from a child with unilateral loss, to one with persistent middle ear effusion, to one with profound loss requiring consideration for cochlear implants. Cases address medical management, parental support, EI referral, and choice of communication options, and are followed by a more detailed expert discussion. Online-EHDI contains information about Pennsylvania’s EHDI program and local assistance. It is linked to the state EHDI program so that when a newborn is referred for not passing screening and the PCP is identified, the physician can be made aware of the course.

The presentation will discuss online education opportunities and marketing them to physicians. Emphasis is on integrating continual learning with EHDI to reach physicians in need of specific knowledge. Coordination with in-depth offerings such as the PediaLink module on hearing loss will also be discussed.

Keywords: Early Hearing Detection and Intervention; internet-based medical education; physician outreach and education
Title: The business case for integrating child health information systems

Author(s): Kristin N. Saarlas, Alan R. Hinman, James Mootrey, Karen Torghele

Affiliation(s): Public Health Informatics Institute, Task Force for Child Survival and Development, 750 Commerce Drive, Suite 400, Decatur GA 30030

Presented by: Alan Hinman

Abstract: Objectives - (1) Understand the rationale/necessity for developing a business case for integrated child health information systems (CHIS), (2) Discuss the elements included in the Business Case Model (BCM) and the results of a pilot study.

Relevance - Current loss to follow-up rates in many early hearing detection and intervention (EHDI) programs are unacceptably high. Integrating EHDI information systems with other CHIS offers a means of improving follow-up. Implications for practice or policy - Analysis of the costs and benefits of integrating EHDI information systems with other CHIS offers policy makers and funders specific relevant data on which to base decisions.

Abstract - Increasing attention is being paid to integration of existing single-purpose information systems in order to improve health and health care. However, policy makers and funders require documentation that the expense involved in integrating systems is worthwhile. With support from the Robert Wood Johnson Foundation and HRSA/MCHB, the Public Health Informatics Institute has developed a model for assessing the anticipated costs and benefits of integrating vital records, immunization registries, newborn dried bloodspot screening, newborn hearing screening, and other CHIS. The BCM uses an Excel™ Spreadsheet which incorporates information on population; incidence, outcomes, and costs of specified conditions; programmatic areas whose information systems are being integrated; coverage and costs of different interventions; and actual or projected improvements resulting from integration of individual information systems. The BCM is pre-populated with state-specific information and allows calculation of the projected costs and benefits in a given state of integrating a variety of CHIS. The model is designed so users can run a basic scenario with minimal training. Because of the current high rate of loss to follow-up in EHDI programs, it seems likely EHDI programs could benefit significantly from integration with other CHIS.

Keywords: child health, health information systems, integration
Title: The Importance of Defining Loss to Follow-up

Author(s): Craig Mason, Scott Grosse, Marcus Gaffney, Denise Green

Affiliation(s): Centers for Disease Control and Prevention (CDC), National Center on Birth Defects and Developmental Disabilities, EHDI Program

Presented by: Craig Mason, Marcus Gaffney, Denise Green, Scott Grosse

Abstract: Ensuring newborns receive recommended follow-up services, such as diagnostic evaluations, has become a key challenge for EHDI programs working to identify infants with hearing loss. In 2004, data indicated that less than half of those referred received a recommended diagnostic evaluation. This resulted in over 50% of infants being described as loss to follow-up (LFU), which is well below the national goal of ensuring all infants receive recommended diagnostic testing. A high LFU rate threatens the overall credibility of EHDI programs. However, it is unclear what exactly this LFU rate means because of variability in how the term is understood and applied. Some use the term to refer to any infants who fail to return for further testing, regardless of reason, while others define LFU as infants who cannot be identified through tracking. The lack of a standard definition makes it difficult to determine a meaningful national LFU rate as well as understand the true extent of this problem, which is important in determining progress towards identifying infants with hearing loss. This presentation will provide examples of different ways to define LFU and show how the use of each definition alters the resulting LFU rate. It will also address the issue of infants being loss to documentation, which occurs when an infant receives follow-up services but no documentation is provided to the state or territorial EHDI program. Through these examples and other related information interested persons will be able to gain a better understanding of LFU rates and the importance of adopting standardized definitions to determine these rates.

Keywords: Follow-up, Data, Tracking
Title: Are We Meeting National EHDI Goals and Addressing Loss to Follow-up?

Author(s): Marcus Gaffney

Affiliation(s): Centers for Disease Control and Prevention (CDC), National Center on Birth Defects and Developmental Disabilities, EHDI Program

Presented by: Marcus Gaffney

Abstract: Through the implementation of EHDI programs in all states and most U.S. territories great progress has been made in identifying infants and children with hearing loss. However, while more infants are now identified with hearing loss, previous data indicates that nearly 50% of infants are not documented to have received recommended EHDI follow-up services, such as diagnostic evaluations. This has generated interest in not only determining progress towards reaching national EHDI goals but also in more accurately quantifying loss to follow-up and understanding the reasons contributing to it. This presentation will provide preliminary data gathered through a new survey to summarize progress towards meeting national goals, including those related to loss to follow-up involving diagnostic and intervention services. These data will include standard indicators such as percentage of newborns screened, completed diagnostic testing for those not passing the screening, number of infants identified with hearing loss, and number of infants enrolled in early intervention. Preliminary data concerning the reasons some infants and children do not receive recommended services will be presented. This information should provide more accurate loss to follow-up rates as well as identifying how programs can help ensure all infants and children receive recommended hearing screening and follow-up services.

Keywords: Follow-up, Data, Tracking, Goals
Title: Results from the MPR Evaluation of HRSA’s National UNHSI Program

Author(s): Shanna Shulman, PhD; Anna Katz, MPH; Henry Ireys, PhD; Melanie Besculides, DrPH

Affiliation(s): Mathematica Policy Research, Inc.

Presented by: Melanie Besculides, Shanna Shulman

Abstract: Since the implementation of the Universal Newborn Hearing Screening and Intervention (UNHSI) program in 2000, the number of infants evaluated for hearing impairment at birth has increased dramatically. Six years after congressional authorization, UNHSI programs are operating in all 50 states, the District of Columbia, and the U.S. territories of Guam, the Northern Marianas, Palau, and Puerto Rico. Despite their significant achievements, UNHSI programs continue to face barriers to full implementation. One of the most urgent challenges involves loss to follow-up among families whose infants screen positive for potential hearing loss. The Maternal and Child Health Bureau (MCHB) contracted with Mathematica Policy Research, Inc. (MPR) to (1) evaluate the progress of the UNHSI program in achieving its goals, and (2) identify barriers to follow-up for infants who require further evaluation and effective strategies for overcoming these barriers. MPR’s assessment of the progress made by the UNHSI program was based on (1) a literature review, (2) survey data collected from 55 state and territorial UNHSI programs, and (3) information gathered during site visits with eight selected state programs involving interviews with program staff, hospital coordinators, audiologists, and PCPs. This session will present the results of MPR’s analysis of these data and its overall assessment of the progress of the UNHSI program since its inception. We will discuss level of program implementation, program outcomes, and barriers to follow-up such as lack of service system capacity, lack of provider knowledge, family challenges in obtaining services, and remaining information gaps. We will also present four emerging themes describing the overall implementation of UNHSI programs and future directions for the program.

Keywords: UNHSI, Loss to follow-up, program implementation
Title: Simplifying Reporting of Communication Development Outcomes

Author(s): Karen Anderson, PhD, Kenneth McCain

Affiliation(s): Florida Department of Health, Children’s Medical Services Early Steps

Presented by: Karen Anderson

Abstract: The Government Performance Results Act requires reporting of the number of children with hearing loss who have developmentally appropriate language and communication skills at school entry and the Joint Commission on Infant Hearing recommends assessment at 6-month intervals using standardized tools. How can an EHDI program working with Part C make it as simple as possible for professionals providing intervention services to obtain appropriate information that is practical to discuss with families and then submit it to service coordinators and the state as simply as possible? This presentation provides information on a Communication Development Monitoring protocol that has easy access materials, a new simple click-and-go reporting with a minimal-fuss update feature, and an electronic submission format that feeds into a data spreadsheet for aggregate analysis at the state level. These materials are web-based and made available at no cost to early intervention providers in Florida.

Keywords: outcomes, development, monitoring, electronic, aggregate
**Title:** Child Outcomes of Early Intervention: A Multi-State Project

**Author(s):** Kathryn Kreimeyer, Ph.D. 1, Allison Sedey, Ph.D. 2, Shirin Antia Ph.D. 3, Arlene Stredler Brown Ph.D. 4

**Affiliation(s):** 1 University of Arizona, 2 University of Colorado – Boulder, 3 University of Arizona, 4 University of Colorado – Boulder

**Presented by:** Kathryn Kreimeyer, Allison Sedey, Shirin Antia, Arlene Brown

**Abstract:** Beginning in Fall 2005, Arizona, Colorado, New Mexico, Idaho, Utah, and Wyoming began a pilot project to collect common demographic information and general development and communication outcome data on approximately 10% of the deaf and hard-of-hearing children served in Birth to Three Early Intervention Programs. One goal of this project is to identify procedures and instruments that promote evaluation of the progress children make when they receive early intervention services. Another goal is to help early interventionists use outcome data to design appropriate intervention for individual children and their families.

Directors of early intervention programs randomly selected children for the project who met the following criteria: permanent bilateral hearing loss, 9 to 30 months of age at initial data collection, no identified significant cognitive disabilities, and English as the primary language used in the home. The early Interventionists collected demographic information and worked with parents to complete general development and communication assessments.

General development was assessed with the Kent Inventory of Developmental Skills for children from 9 to 14 months of age and with the Child Development Inventory for children from 15 to 36 months of age. Communication development was assessed with the MacArthur-Bates Communicative Development Inventory.

In this presentation, outcome data for 50 children who participated in the pilot study will be presented. Additionally, for 20 of the children, data on performance over time will be presented.

In addition to sharing the data obtained on these multiple assessments, presenters will discuss the challenges encountered in this multi-state project and plans to expand this project in the future.

**Keywords:** Early Intervention, Outcomes
Title: Adapting EI for Children with Auditory Neuropathy

Author(s): Roxanne J. Aaron, Betsy Moog Brooks

Affiliation(s): The Moog Center for Deaf Education

Presented by: Roxanne Aaron, Betsy Moog Brooks

Abstract: Regular clinical use of otoacoustic emissions and auditory brainstem response testing has increased the number of infants who present to early intervention programs with a diagnosis of auditory neuropathy. Children with this same diagnosis may have very different responses to auditory signals and diverse educational needs. This is related in part to the variety of underlying mechanisms that can yield a diagnosis of auditory neuropathy. Subsequently there is a lack of agreement on how to help children labeled with this disorder learn to communicate. While children with auditory neuropathy may have poor word recognition ability, they are enrolling in early intervention before their ability to understand words can be assessed. Several children with a diagnosis of auditory neuropathy have attended the Moog Center for Deaf Education. Case presentations will illustrate audiological and educational strategies used for early intervention. The use of hearing aids, FM systems, and cochlear implants to support access to sound will be discussed. The use of diagnostic teaching to assess auditory skills and communicative prognosis will be explored.

Keywords: Roxanne J. Aaron, MA, CCC-A, FAAA, raaron@moogcenter.org, (314) 692-7172