

Title: Audiological Protocol and Data Management in the CMV and Hearing MultiCenter Screening (CHIMES) Study

Author(s): Faye P. McCollister, EdD, CCC-A, CED 1; Diane Sabo, PhD, CCC-A 2; Karen Fowler, DrPH 3; Site Audiologists 4

Affiliation(s): 1 Associate Professor Emeritus, University of Alabama, Tuscaloosa Audiology Consultant, NCHAM, Utah State University, Logan and CHIMES Study, University of Alabama at Birmingham; 2 Associate Professor, Department of Communication Sciences, University of Pittsburgh, Audiology Consultant, NCHAM, Utah State University, Logan and CHIMES Study, University of Alabama at Birmingham; 3

Presented by: Faye McCollister, Diane Sabo, Karen Fowler

Abstract: The NIDCD CHIMES Study will screen 100,000 subjects for congenital CMV infection and provide audiological monitoring during the project for children identified as CMV positive. It is thought that this congenital infection is responsible for about one third of all pediatric hearing loss and has significant impact on public health services. However, the characteristics of the associated hearing loss, even though studied for more than 40 years, are not fully known. The CHIMES Study audiological protocol and data management procedures/forms have been developed with consultation with experts in pediatric audiology and review of published protocols. This multicenter investigation has included two planning meetings, conference calls, and frequent exchange of draft documents in order to facilitate development of mutually acceptable procedures and ensure consistency in methodology across and within sites. Audiology protocols and documents for data management will be shared and input will be solicited.

Keywords: CMV, Hearing Loss, Audiology Protocols, Data Management

Title: Multistate Study of Etiology In Newborn Hearing Screening

Author(s): John C. Carey 1, Karin M. Dent 1, Janice C. Palumbos 1, Bronte Clifford 1, Rong Mao 1, Richard Harward 2, Nita Jensen 2, Karl White 2, Richard Smith 3, John Eichwald 4, Krista Biernath 4, Sylvia Au 5, Patricia L. Heu 5, Elaine Marr 5, Lianne Hasegawa 5, Kirsty McWalter 5, Dianne Abuelo 6, Jeff Milunsky 6, Kristilyn Zonno 6, Julie Jodoin-Krauzyk 6, Cindy Benson 6, Betty Vohr 6

Affiliation(s): 1 University of Utah, 2 Utah Department of Health, 3 University of Iowa, 4 Centers for Disease Control, 5 Hawaii Department of Health, 6 Rhode Island Department of Health

Presented by: John Carey

Abstract: Genetic mutations account for approximately 50% of congenital hearing loss (HL), and about 80% of genetic deafness is nonsyndromic, usually autosomal recessive. Mutations of the GJB2 gene, encoding the connexin 26 protein (Cx26), account for up to 50% of nonsyndromic autosomal recessive deafness in some populations. Most past studies of the etiology have been performed in schools for children with deafness or in specialty clinics. Currently over 40 states in the U.S. have established newborn hearing screening (NHS) programs, providing opportunity to investigate the etiology in a population-based cohort. Three states, UT, RI, and HI, are collaborating in a CDC-funded investigation of HL etiology ascertained through state programs. The study's aims are to: 1) classify the causes of congenital HL; 2) determine the frequency of GJB2, GJB6 and 2 mitochondrial mutations; and 3) identify issues surrounding linking genetic services with NHS and follow-up (EHDI). Participants with confirmed permanent HL are offered a comprehensive medical genetics evaluation and testing for GJB2, GJB6 and the mitochondrial mutations. To date, 170 probands and immediate family members have been evaluated. We have identified 89 cases with nonsyndromic bilateral sensorineural (SN) HL, 39 with syndromic HL, and 42 with other (conductive, acquired or unilateral SN). Sixteen of the cases (18% of nonsyndromic SN cases) were found to have biallelic mutations in GJB2. One mitochondrial mutation has been found in this population and it is likely not the cause of the hearing loss in that case. This multistate investigation is the first to determine the causes of HL in a population ascertained through NHS. The results of this study could help facilitate the incorporation of clinical genetic services into EHDI. Determining the etiology of HL is important in patient management and detection of GJB2 mutations may preclude other diagnostic testing.

Keywords: Genetic deafness, Connexin 26, Syndrome

Title: Consumer Attitudes towards Genetic Testing and Newborn Screening

Author(s): Kathleen S. Arnos 1, Sarah Burton 1, Kara Withrow 2, Andrea Kalfoglou 3, Arti Pandya 2

Affiliation(s): 1 Department of Biology, Gallaudet University, Washington, DC, 2 Department of Human Genetics, Virginia Commonwealth University, Richmond, 3 Social and Behavioral Research Branch, National Human Genome Research Institute, National Institutes of Health

Presented by: Kathleen Arnos

Abstract: The introduction of early hearing detection and intervention programs (EHDI) and the recent progress in identification of genes for deafness has led to greater utilization of genetic services by parents of children identified with hearing loss (HL). However, efforts to assess consumer attitudes toward genetic testing for HL have lagged behind. We held five focus groups with 44 participants to explore their attitudes towards genetic technologies, motivation for seeking genetic testing, views about newborn hearing screening and reactions to the idea of adding molecular screening for HL at birth. Focus group participants included hearing parents of deaf children, Deaf parents and young Deaf adults of diverse ethnic backgrounds. Trained moderators presented a series of questions and the discussions were recorded and transcribed. A team of co-investigators reviewed the transcripts to identify major themes and developed a qualitative coding structure. The data were coded using the qualitative data analysis software NVivo 4.0. Perceived benefits of newborn screening and genetic testing for HL included helping parents 1) accept the diagnosis 2) share results with family members, 3) anticipate the need for medical care, and 4) assess chance of having additional children with HL. Attitudes about the timing for providing genetic evaluation and testing were mixed; participants placed emphasis on respecting variations in the readiness of the family. Several parents expressed an interest in being offered molecular screening for common deafness genes early, potentially as an adjunct to audiologic newborn hearing screening. However, a recurring concern was the cost effectiveness and the need for parental consent. The results from this analysis will guide the development of a comprehensive and sensitive survey instrument to be used on a national level. This information will be used to develop policy related to the implementation and timing of molecular screening for common genes for hearing loss.

Keywords: genetics, hearing loss, focus groups, molecular testing

Title: Developing Community Partnerships for Cultural Diversity Training

Author(s): Jill Ellis, M.Ed.

Affiliation(s): 1 Center for Early Intervention on Deafness, Berkeley, California, 2 UC San Francisco, 3 Children's Hospital-Oakland, California, Alameda Health Consortium, Asian Community Mental Health

Presented by: Jill Ellis

Abstract: Research emphasizes that providing information about hearing loss to families significantly impacts parent decisions and involvement in their children's early intervention. However, in order to be successfully assimilated and meaningfully pursued by families, information must be culturally relevant in order to be understandable and useful. Only recently have increasing efforts been devoted to considering the unique perspectives, reactions, and needs of families from culturally diverse populations receiving a diagnosis of the child's deafness and the myriad of suggestions and options for interventions.

For Medical Home and pediatric providers, overlooking culturally sensitive communication and practices increases the risk that treatment protocols will not be fully understood or followed, and timely interventions will not be taken.

This presentation will address one Center's approach to partnering with community health providers working with culturally diverse families, increasing their awareness, understanding, and skills needed to effectively impart information, encouraging parent participation and advocacy. Endorsing the definition of "cultural identity" - the (feeling of) identity of an individual, influenced by his/her belonging to a group/culture, we will address this complex phenomenon, with examples, materials and strategies designed to address the impact of differences of languages/syntax, dress and traditions, beliefs/values as they relate to a child with hearing loss, and the family's interactions with professionals.

This project found positive outcomes from partnering with Medical Home providers who learned and successfully implemented skills to raise their awareness, as well as effectively increase their communication strategies, within their culturally diverse populations. After attending this presentation, participants will be able to identify examples of effective approaches to use with families of Hispanic, Asian and Middle Eastern backgrounds, including: Language (verbal and body language), Beliefs/Values (attitudes to disabilities), Social Conventions, Interactions with the Majority Culture (attitudes to authority figures, including doctors, therapists.)

Keywords: Cultural Diversity – Professional Competency

Title: Expanding Skills of Providers and Culturally Diverse Families

Author(s): Jill Ellis, M.Ed., Cynthia Wong, M.A., Maryam Salehomoum, M.A. CCC-SLP

Affiliation(s): 1 Center for Early Intervention on Deafness, Berkeley, California, 2 UC San Francisco, 3 Children's Hospital-Oakland, California, 4 Asian Community Mental Health

Presented by: Jill Ellis

Abstract: Adapting and Expanding Knowledge and Skills of Early Intervention Provides and Parent Education Materials to Respond to Culturally Diverse Populations

For early intervention programs to be successful, they must not only provide a comprehensive service delivery program with expertly trained staff (including teachers of the deaf, speech therapists, audiologists, mental health and medical specialists,) but they must also consider and support the diverse cultural and linguistic backgrounds and needs of all families. Research proves that gaining awareness of culturally diverse customs and perspectives, along with skills to impart sensitive communications, significantly increases the opportunities for families to accept and use intervention strategies that help promote a child's progress and overall success.

To that end, this presentation will discuss one Center's approach to enhancing the attitudes, knowledge and skills of the early intervention multidisciplinary team members who work with families representing diverse cultural backgrounds in both home and center based environments. Special examples will outline this program's adaptations and expansion of intervention strategies and materials (including vocabulary books, sign language video tapes and staff trainings) created specifically for working with families of Hispanic, Middle Eastern, and Asian backgrounds.

After attending this session, participants will be able to identify examples of effective (and ineffective) communications and interventions for communicating EHDI relation information to parents of culturally diverse backgrounds, as well as describe activities that will help them expand their own resources and materials used in their respective programs. Participants will gain an understanding of how: (1) Language (verbal, body language, syntax and phonetic structures) Beliefs/Values (particularly attitudes to disabilities, hearing loss, amplification, surgery); (2) Social Conventions; (3) Interactions with the Majority Culture (with particular reference to attitudes to authority figures, such as teachers, therapists, audiologists, doctors, etc.) are viewed by various cultural perspectives.

Keywords: Families, culturally diverse, attitudes

Title: Arizona Strategies to Reduce Loss to Follow-up

Author(s): Lylis E Olsen, MS, MPH, Randi Winston, AuD, Jan Kerrigan, RN, Christy Taylor, Data Specialist

Affiliation(s): The EAR Foundation of Arizona, Arizona Department of Health Services

Presented by: Jan Kerrigan, Christy Taylor

Abstract: In 2005, sixty percent of children in Arizona who did not pass the birth hearing screening had unknown outcomes beyond what was reported from the initial hospital discharge. Reporting was voluntary and there were no coordinated central follow-up services. In May 2005, legislation was passed to require reporting of hearing screening and testing data. With the completion of rules in April 2006, the reporting requirements and central follow-up was implemented. The new law required a central database to enable active follow-up conducted by the Arizona Department of Health Services. In less than a year, the loss to follow-up rate decreased from 60% to approximately 20%. The identified factors that will be discussed include: (1) Improved reporting of data; (2) Changes in the way that hospital programs were trained and procedures developed; (3) Better tracking through the hospital screening programs; (4) Community participation in development of reporting forms and procedures; (5) Collaboration between hospital, audiologist, medical home and early intervention; (6) Education of health care providers

The learner will: (1) be able to identify the primary components of the centralized follow-up program; (2) understand the role of community participation in program development; (3) identify at least one new potential collaborative partner in their own community

Keywords: Newborn Screening, EHDI, Follow-up, Training, Data Management

Title: Taking EHDI's Pulse: Conferences as Strategic Change Agents

Author(s): Molly Crawford 1, Penny Hatcher 2

Affiliation(s): 1 Health Educator, Newborn Screening, Minnesota Department of Health, 2 Supervisor, Child Health Programs/EHDI & UNHSI Project Director, Conference Grant Coordinator, Minnesota Department of Health

Presented by: Molly Crawford

Abstract: In April 2006, The Minnesota Department of Health (MDH) convened a statewide multi-disciplinary early hearing detection and intervention (EHDI) Summit, which was supported in part by a public health conference grant from the Centers for Disease Control and Prevention (CDC).

MDH will share strategies and methodologies behind the Summit that were used to affect change. Find out what MDH learned from evaluations and pre and post-tests. See how the Summit's "Call to Action" brought responsibility and accountability for EHDI success to a personal level and how it helped remove barriers to implementation. Identify how Minnesota's 16 education-based EHDI teams were key to forging local community partnerships and strengthening collaborative efforts. MDH will present tips for planning your event.

The Summit brought more than 150 parents, health professionals, educators, and early interventionists together. The Summit addressed best practices, statewide strategies, program goals, and future system enhancements. It included a recognition dinner, full day conference, networking, exhibits, and vendors. The Summit was unique because it blended audiences, communicated intentional and purposeful action messages, and incorporated measurement tools MDH used to take the pulse on EHDI in Minnesota.

Evaluations rated the Summit high. Pre and post-tests showed an increase in knowledge. Participants completed a "Call to Action" form by listing action items and activities that they could do to further the goals of EHDI in Minnesota. The final evaluation revealed actions that directly resulted from the Summit. Evaluations provided ideas for future education and awareness activities and training needs such as one-on-one state workgroup and EHDI team meetings, regional trainings, and a need for shared goals and commitment to following infants who fail or miss their hearing screen.

Keywords: collaboration, early intervention, parent education, provider education, meeting

Title: Factors Associated with Lost to Follow-up in Massachusetts

Author(s): Jessica MacNeil, Chia-ling Liu, Sarah Stone, Janet Farrell

Affiliation(s): Center for Community Health, Massachusetts Department of Public Health

Presented by: Jessica MacNeil

Abstract: Appropriate follow-up with families from screening to definitive diagnosis and intervention is the most important element to ensure success of Early Hearing Detection and Intervention Programs. Approximately 10% of Massachusetts children who did not pass hearing screening become lost to follow-up on the audiologic evaluation, and approximately 25% of those with hearing loss do not receive Early Intervention (EI) services. We used data from the Massachusetts Childhood Hearing Data System and Early Intervention Information System to identify factors associated with becoming lost to follow-up on the audiologic evaluation for Massachusetts infants who did not pass a hearing screening and EI services for those with hearing loss. Factors evaluated included child's birth weight and hearing screening/diagnostic results; and maternal age, race/ethnicity, marital status, parity, smoking status during pregnancy, educational attainment, primary language, health insurance status, and region of residence. A discussion of the findings and their bearing on follow-up efforts will be the focus of this presentation. Massachusetts has excellent follow-up rates overall, however our analyses allow the program to prioritize limited resources to subgroups of infants who are at higher risk of becoming lost to follow-up.

Keywords: Early Hearing Detection and Intervention, Lost to Follow-up, Early Intervention

Title: Washington State's Tracking and Surveillance System for Audiologists

Author(s): Karin Neidt, MPH

Affiliation(s): Washington State Department of Health, Genetic Services Section

Presented by: Karin Neidt

Abstract: Collecting accurate and up-to-date diagnostic information from audiologic evaluations is an important yet challenging piece of Early Hearing Detection and Intervention (EHDI) tracking and surveillance systems. Washington State has developed a secure web-based application for pediatric audiologists to report clinical information on newborns seen at their clinics. This system was developed in 2003 and implemented in 2004. Since then the Washington EHDI program has used this system to collect demographic, risk factor, diagnostic, and ongoing medical management information for approximately 1200 patients referred for audiologic evaluations.

This presentation will give an overview of the Washington EHDI program's web-based application, how it was developed, what features it offers to audiology clinics for their own case management, and pros and cons of the system. Lessons learned by the Washington EHDI program from data collected using this system and plans for the future will also be discussed.

Keywords: web-based application, diagnostic results, audiologists

Title: A Comprehensive Analysis of an EHDI Program: A Retrospective Study

Author(s): Vickie Thomson, MA 1, 2

Affiliation(s): 1 Colorado Department of Public Health and Environment, 2 University of Colorado

Presented by: Vickie Thomson

Abstract: The Colorado Infant Hearing Program began in 1992 as a pilot project and then was legislated to require all birthing hospitals to offer a newborn hearing screen. Funding from the Centers for Disease Control has enabled Colorado to develop an active and passive data management and tracking system to assure that infants who are missed or fail a screen receive timely and appropriate follow-up through diagnosis and early intervention services. An analysis of the Colorado Infant Hearing Program will be presented focusing on those infants who did not meet the JCIH recommendation of screening by 1 month, diagnosis by 3 months and enrollment into early intervention by 6 months. Data from 2001-2004 will determine what factors are associated with: infants not receiving an initial screen prior to hospital discharge; not receiving an outpatient rescreen or diagnostic evaluation; and infants who pass newborn hearing screen but are subsequently diagnosed with a permanent hearing loss. These analyses will assist the Program in evaluation, planning and implementing best practices. Despite having one of the most successful newborn hearing screening programs in the world, Colorado still finds substantial room for improvement. In all likelihood, these findings also have similar application to other universal hearing screening programs inside and outside the United States.

Keywords: Colorado Infant Hearing Program, Data management system, Data analysis, Program evaluation, Program implementation

Title: NYS Early Intervention Program Clinical Practice Guidelines

Author(s): Cynthia Mack, Brenda Knudson Chouffi, Independent panel of professionals and parents

Affiliation(s): Sponsored by the New York State Department of Health, Bureau of Early Intervention

Presented by: Cynthia Mack, Brenda Chouffi

Abstract: Objectives: 1). Define and present the rationale for the use of evidence-based clinical practice guidelines in the delivery of early intervention services. 2). Access the three versions of the New York State Department of Health (NYSDOH) Clinical Practice Guideline on Hearing Loss. 3). Present the purpose of using the Clinical Practice Guideline on Hearing Loss to help determine appropriate assessment and intervention strategies for young children with hearing loss.

Relevance: The purpose of the Clinical Practice Guideline is to provide parents, clinicians, and others with recommendations based on the best specific evidence available about “best practices” for assessment and intervention for young children with hearing loss.

Implications: The Clinical Practice Guidelines outline best practices and scientifically based research, a requirement of Individuals with Disabilities Education Improvement Act of 2004.

Summary of Content: In 1996, a multiyear effort was initiated by the NYSDOH to develop clinical practice guidelines to support the efforts of the statewide Early Intervention Program (EIP). As lead agency for the Early Intervention Program in New York State, the NYSDOH is committed to ensuring that the EIP provides consistent, high-quality, cost-effective, and appropriate services that result in measurable outcomes for eligible children and their families.

The Clinical Practice Guideline on Hearing Loss, released in 2006, is intended to help families, service providers, and public officials by offering recommendations based on scientific evidence and expert clinical opinion on effective practices. To ensure a credible product, an evidence-based, multidisciplinary consensus panel approach was used.

Keywords: Clinical Practice Guideline, Early Intervention, best practices, evidence-based, scientifically based

Title: Wisconsin's Innovative Parent Support Activities

Author(s): Laurie Nelson

Affiliation(s): 1 Wisconsin Educational Services Program for the Deaf and Hard of Hearing (WESPDHH) –Outreach, 2 Wisconsin Families for Hands and Voices

Presented by: Laurie Nelson

Abstract: In Wisconsin, parents have been recognized as crucial collaborating partners in the development of parent support activities. As a result, a variety of innovative programs that truly meet the needs of parents have been implemented, as well as the development of a "Parent Liaison" position that is filled by the parent of a hard of hearing child. This presentation will focus on the evolution of these programs, beginning with the 2003 Parent Summit, which provided a crucial blueprint for the state for the development of services, the Guide-By-Your-Side and Follow-Through Programs, the Deaf Mentor Project, the Parent Notebook, the annual Statewide Parent Conference and the outgrowth of the Distant Pals Program, as well as the initiation of statewide parent support groups, including Hands and Voices and AG Bell. In addition, Wisconsin's efforts to develop culturally sensitive programming for bilingual (ASL, Spanish, and Hmong) families will be discussed. Future plans for parent support opportunities will also be outlined, including coffee clutches for families with a newly diagnosed child, and ongoing in-home support for families opting for an auditory/oral focus for their child. Collaboration has been key in the development of these programs, and participants will have the opportunity to discuss strategies for developing strong collaborations. Additionally, as an outgrowth of Wisconsin's activities, parent leadership has increased significantly. Participants will also have the opportunity to learn from Wisconsin's lessons in this process, discuss the difference between parent-to-parent support and parent-to-professional support and review the benefits of supporting state-level parent leadership.

Keywords: Parent Leadership, Support Activities

Title: Characteristics of Congenital Hearing Loss Identified by Newborn Hearing Screening

Author(s): Barbara S. Herrmann, Ph.D.

Affiliation(s): Harvard Medical School, Massachusetts Eye and Ear Infirmary

Presented by: Barbara Herrmann

Abstract: The optimization of newborn hearing screening implementation is contingent upon accurate delineation of the types of hearing losses present in the newborn nursery. Analysis of data from five years of newborn hearing screening in a major teaching hospital nursery (N=21,058) using a single hearing screening (AABR; Natus Medical) indicated that 98% of the babies passed in both ears and 2 % of the babies referred in one (1.5%) or both (0.6%) ears. Eighty-eight percent of referring infants returned for a full evaluation using evoked response audiometry within three weeks of the hearing screening. Approximately one-third of those infants had documented hearing loss; Of the bilateral refers, 34% had normal hearing on follow-up and 66% had hearing loss (hearing sensitivity threshold for toneburst stimuli poorer than 20 dB HL). Of the unilateral refers, 80% had normal hearing on follow-up and 20% had hearing loss. Degree of hearing loss was characterized by the hearing sensitivity for a 2000 Hz toneburst. One third of the hearing losses identified had borderline normal to mild loss hearing sensitivity (20 – 35 dB HL threshold at 2000 Hz). One third of the infants had moderate hearing sensitivity at 2000 Hz (40 – 65 dB HL threshold) and the final third had hearing sensitivity at 2000 Hz of 70 dB HL or poorer. Repeat AER evaluations and later behavioral audiograms on these same children indicate that most of the sensorineural hearing losses were stable over the first two years.

Keywords:

Title: Genetic Counseling for Congenital Hearing Loss: Lessons from a Multistate Study of Etiology

Author(s): Karin M Dent 1, Janice C Palumbos 1, Bronte Clifford 1, Rong Mao 1, Richard S Harward 2, Nita Jensen 2, Richard Smith 3, Sylvia Au 4, Patricia L Heu 4, Lianne Hasegawa 4, E. Marr 4, Kirsty McWalter 4, Dianne Abuelo 5, Kristilyn Zonno 5, Julie Jodoin-Krauzyk 5, Jeff M Milunsky 6, Cindy Benson 5, Betty Vohr 5, Karl White 7, John C Carey 1

Affiliation(s): 1 University of Utah Medical Center, 2 Utah Department of Health, 3 University of Iowa, 4 Hawaii Department of Health, 5 Women and Infants Hospital of Rhode Island, 6 Boston University, 7 Utah State University.

Presented by: Karin Dent

Abstract: Approximately 50% of congenital hearing loss (HL) is attributed to genetic causes, 80% of which is nonsyndromic, usually autosomal recessive. Mutations in the GJB2 gene, encoding the connexin 26 protein, account for up to 20% of all congenital HL and 50% of nonsyndromic autosomal recessive deafness.

Utah, Rhode Island, and Hawaii are collaborating in a CDC-funded investigation of HL etiology in a cohort ascertained through state newborn hearing screening (NHS) programs. The study's aims are to classify the causes of congenital HL; determine the frequency of GJB2, GJB6, and two mitochondrial mutations (A1555G and A7445G); and identify issues surrounding coordination of genetic services and early hearing, detection, and intervention programs. To date, 170 probands and their immediate family members have participated in a comprehensive medical genetics evaluation with testing for GJB2, GJB6, and mitochondrial mutations. 127 cases (75%) have nonsyndromic HL. Of these, 14 individuals had isolated microtia and/or aural atresia, 24 had unilateral sensorineural (SN) HL, and 89 had bilateral SNHL. Sixteen of the 89 (18%) had biallelic mutations in GJB2. Thirty-nine children were diagnosed with syndromic HL and 4 had acquired HL. Etiology was identified in 73 (43%) study participants. A mitochondrial mutation (A1555G) was identified in a microtia patient. No GJB6 mutations were identified.

Determining the etiology of congenital HL is important for patient management, prognosis, recurrence risk, and anticipatory guidance and allows for accurate genetic counseling. Syndrome recognition permits a better prediction of course for an individual. Because GJB2 deafness is associated with normal cognitive development, lack of progression, and no additional medical complications, identification of GJB2 mutations precludes other diagnostic testing. Additionally, evidence of GJB2 genotype/phenotype correlation where truncating mutations are associated with more severe hearing loss guides interventions (cochlear implant). We strongly recommend incorporating genetic counseling services into newborn screening programs.

Title: Does UNHS Identify all Children with GJB2 (Connexin 26) Deafness?

Author(s): Virginia Norris, Kathleen Arnos, Wendy Hanks, Xia. Xia, Walter Nance, Arti Pandya

Affiliation(s): Gallaudet University, Washington, D.C.

Presented by: Wendy Hanks

Abstract: In the US, EHDI programs have been implemented with the goal of identifying prelingual hearing loss so that medical, educational, and audiological intervention services can be initiated. Data from these programs suggest that in this country, clinically significant hearing loss is present in 1-2 per 1,000 infants at birth, and nearly 3 per 1,000 by the age of four. Although there is extreme heterogeneity in the etiology of hearing loss, mutations in a single gene, GJB2 (connexin 26), are the most common genetic cause of deafness in many populations. Recessively-inherited GJB2 mutations typically lead to congenital, moderate to profound, sensorineural hearing loss. Cases with milder and/or progressive losses including cases with apparent postnatal onset have been described however. We will present the cases of eleven children, all with two pathogenic GJB2 mutations, who passed their hospital-based newborn hearing screening tests. Their hearing loss was not confirmed audiotically until 12-60 months of age. Parents were interviewed and medical records were reviewed. Screening for mutations was performed by DNA sequencing of the GJB2 gene and revealed six 35delG homozygotes, and three compound heterozygous for a 35delG mutation and a second pathogenic mutation. Three subjects had a positive family history of hearing loss, while six were simplex cases. Our cases, in addition to previous reports indicate that connexin deafness may not be fully penetrant at birth. It is not clear if these cases reflect false negative hearing screening test results, examples of delayed onset hearing loss or infants with progressive losses that were subclinical at birth. It is important to consider GJB2 mutations as an etiology of hearing loss in any child with non-syndromic, recessive or sporadic hearing loss regardless of early audiotologic hearing screening results.

Keywords: genetic hearing loss, Connexin 26, newborn hearing screening, progressive hearing loss

Title: Development of a Multidisciplinary Hearing Assessment Clinic in Utah: The Rationale and Preliminary Outcomes

Author(s): Albert H. Park, MD 1, John C. Carey, MD 2, Steven B. Bleyl, MD 2, Cache Pitt MS, CCC-A 3

Affiliation(s): 1 Division of Otolaryngology- Head and Neck Surgery, University of Utah; 2 Division of Medical Genetics, Department of Pediatrics, University of Utah; 3 Audiology, Primary Children's Medical Center

Presented by: Albert Park, John Carey, Cache Pitt

Abstract: In 2005, a state-wide survey was sent to parents of children with sensorineural hearing loss asking about their experiences with the testing and treatment of their child's condition. One hundred eight of three hundred eighty-nine families surveyed responded. In summary, twenty-two percent of the primary care physicians were not involved in any aspect of the child's hearing evaluation. Forty percent of the patients underwent four or more audiologic tests prior to a diagnosis. The most common reason for delayed diagnosis was difficulty in obtaining an appointment with an audiologist (26%) followed by an inability to obtain a referral from the primary care physician (12.8%) and multiple testing (12.8%). Sixty percent of the families noted that the steps to diagnose their child's hearing loss were difficult.

A multidisciplinary hearing assessment clinic (MHAC) was developed to address parental frustrations with the diagnostic and therapeutic process in Utah. The clinic consists of pediatric audiology, otolaryngology and genetics. Primary care, ophthalmology, early intervention, and social services participate in this clinic in a more informal manner but provide crucial input for patient management. The goal of this clinic has been to provide information and resources to families about pediatric hearing loss, expedite the screening and diagnostic process for a child with suspected hearing loss and to establish research projects to improve hearing outcomes and care. The objectives of the proposed presentation are as follows: (1) present examples of the important role an MHAC clinic plays in the evaluation and treatment of newborn hearing loss (2) present important issues that anyone dealing with childhood hearing loss needs to know (3) provide a proposed paradigm for the evaluation of newborn hearing loss. The content of this conference should be relevant to anyone dealing with childhood hearing loss. Such a clinic will hopefully encourage similar efforts nationwide to improve parental satisfaction and patient outcomes.

Keywords: Multidisciplinary hearing assessment clinic, pediatric audiology, otolaryngology, genetics

Title: First Contacts: A Guide for Parents and Professionals

Author(s): Janet Gilbert, Diane Fekete, Mary Ann Lyon, Susan Swartz, Richard Totin

Affiliation(s): Oakland Intermediate School District

Presented by: Janet Gilbert, Mary Lyon

Abstract: Research identifies the need for early identification and intervention for deaf and hard of hearing infants by 6 months of age, with health care and educational providers working together in a coordinated system of services for parents. In addition, the experts at the National Consensus Conference on Effective Educational and Health Care Interventions for Infants and Young Children with Hearing Loss, September 10-12, 2005, recommended that professionals not only coordinate services, but that all professionals who have early contacts with parents be well informed about hearing loss and communicate effectively with families throughout the screening and evaluation process (Marge and Marge, 2005). Often, though, there is a division of services, lack of communication between professionals in separate disciplines and lack of information about hearing loss and the range of services available for families. In order to ensure that professionals in Oakland County, Michigan were well informed and to encourage communication, a resource kit was developed to provide them with the information they needed in an easy to use format. During interviews and numerous stakeholder meetings, parents and professionals identified three areas of professional need: 1) how to share sensitive information and understand parents; 2) the crucial need to understand hearing loss and move quickly to treatment and 3) awareness of the range of educational options. A 15 minute DVD to assist professionals in delivering sensitive information and a county referral guide were developed and packaged with an existing 30 minute video about hearing loss for the county resource kit. In this presentation, participants will be 1) guided through a process to identify needs; 2) introduced to the components of the kit and their relevance and 3) provided resources for obtaining components for development of kits tailored to their needs.

Keywords: Professional awareness; information dissemination; sensitivity

Title: Utilizing a Statewide Immunization Registry for EHDI Tracking and Reporting

Author(s): Kathryn P. Aveni 1, RNC, MPH, Zina Kleyman 2

Affiliation(s): 1 New Jersey Department of Health and Senior Services, Early Hearing Detection and Intervention Program; 2 New Jersey Department of Health and Senior Services, Office of Information Technology Services

Presented by: Kathryn Aveni

Abstract: New Jersey law (P.L. 2001, ch. 373) requires the Department of Health and Senior Services to “establish a central registry of newborns identified as having or being at risk of developing a hearing loss, for the purposes of compiling statistical information and providing follow-up counseling, intervention and educational services to the parents of the newborns listed in the registry.” Oversight for implementation of this legislation is the responsibility of the New Jersey Early Hearing Detection and Intervention (EHDI) Program. The EHDI Program has partnered with the New Jersey Immunization Information System (NJIIS) for monitoring and reporting of newborn hearing testing. The objectives of this partnership are to use this web-based electronic immunization registry to allow primary care providers to view information about their patients’ hearing screening and follow-up status; and to allow audiologists and other providers who perform outpatient audiologic evaluation to report results electronically and efficiently to the EHDI program. Prior to this partnership, the EHDI program received inpatient hearing screening results from the Electronic Birth Certificate (EBC), and outpatient exams were reported on paper forms and keyed into an EHDI-created database. The NJIIS-EHDI interface was rolled-out beginning in September 2006. The NJIIS application, already using the EBC to populate their system, was extended to include the EHDI-related fields from the EBC, allowing providers to view the inpatient hearing screening results. Audiologists are given system access to submit outpatient follow-up reports via an on-line interface. This provides the data to the EHDI program and also allows immediate viewing of the results by the primary care provider. The presentation will demo user interface , describe the system functionalities, discuss the challenges encountered during application development and roll-out to the users, and will review successes and feedback from users.

Keywords: Hearing Screening, Immunization, Online Databases, Information Systems

Title: Quality assessment of Minnesota newborn hearing screening data: A pilot study

Author(s): Katherine James, Judy Punyko, Sarah Solarz, Yaoli Li

Affiliation(s): Minnesota Department of Health

Presented by: Yaoli Li

Abstract: Routine assessment of data quality is essential to ensure that public health information is valid and reliable. With this in mind, the Minnesota Department of Health (MDH) Maternal and Child Health Section (MCH), Environmental Health Division (EH), and Center for Health Statistics (CHS) commenced a joint pilot study in February 2006 to assess the quality of Minnesota newborn hearing screening records. Information found in medical records (the “gold standard” source of data) was compared to information found in the MDH newborn hearing screening database. Select data fields from Minnesota newborn hearing screening records were abstracted from 200 randomly selected infants’ medical records at 20 birthing hospitals across the state. Overall, the MDH hearing screening database was found to contain quality data, though some problems were identified. For the 200 infants sampled, 29% of the hearing screening dates recorded in medical records did not match dates found in the MDH database, while 10.5% of the dates recorded in the database were missing entirely. “Refer” (failed) hearing screening results recorded in medical records often did not match results recorded in the hearing screening database (specificity: 20% and 25% for left and right ears, respectively). “Pass” results from medical records, however, matched hearing screen results from the MDH database close to 95% of the time. These results suggest that less frequently recorded events – such as failed hearing screening results, parental refusals for hearing screening, or infants who are transferred to other hospitals – have a higher level of disagreement comparing medical record data to hearing screening data. MDH staff plan to reassess data entry practices and refine our study protocol with the ultimate goal of conducting routine quality assessments based on a probability sample survey design using a larger overall sample size.

Keywords: Data Quality, Newborn Hearing Screening, Medical Record Abstraction

Title: Knowing What You Have: Quality Assurance Activities in EHDI Programs

Author(s): Pamela Costa, MA

Affiliation(s): Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disability, Early Hearing Detection and Intervention

Presented by: Pam Costa

Abstract: Over the past decade, state EHDI programs have implemented and improved their EHDI systems. More recently, states have been initiating a variety of activities to determine program coverage, completeness, and accuracy. These activities are critical not only for program evaluation, but also, for improving the overall system and data collection. Without such efforts, states may not really know the accuracy of their data, or understand the percentage of children with hearing loss not represented in their systems. Implementation of some activities may also reduce loss to follow-up by identifying components of their systems that are not working, as well as providing states the means to better communicate with key partners.

Some examples of the quality assurance activities implemented by states include visiting hospitals and reviewing medical records, linking to other data bases (such as birth certificates, birth defects, metabolic, Medicaid) to potentially identify missed children, submitting reports back to hospitals for clarification, and monitoring the number of children identified by some geographical distribution. This presentation will provide concrete examples that could be considered, and then adopted (with or without modification) by other states to assess their own systems. Additionally, the session will engage the audience as to the feasibility of the activities, identifying potential barriers, and seeking solutions which support implementation.

Keywords:

Title: Counseling Guidelines: Supporting children with hearing loss

Author(s): Eileen Rall, Au.D., CCC-A, Louise A. Montoya, MA, LPC, CSC

Affiliation(s): Center for Childhood Communication of The Children's Hospital of Philadelphia

Presented by: Eileen Rall

Abstract: Audiologists receive minimal training in supporting the psychosocial development of our pediatric patients. Of all the professionals in a child's life, audiologists are among the few that understand well the negative impact of hearing loss on a child's relationship with their family, friends and school. It is well within our scope of practice to help reduce the negative effects that hearing loss can have on a child's psychosocial development.

This session will review Erik Erikson's model of psychosocial development and normal child development of self-concept/self-esteem for children from birth through transition into school. There are many ways an audiologist can support healthy psychosocial development by enhancing communication skills beyond providing appropriate amplification systems and supporting auditory development. Developmental counseling guidelines that can be used by audiologists to help facilitate healthy psychosocial development, development of a positive self-concept and age-appropriate social skills will be reviewed. These guidelines address issues that may arise with families at the time of their child's diagnosis and suggest steps audiologists can take to facilitate the family's healthy acceptance of the diagnosis. The guidelines also offer strategies for working directly with the child on their communication skills that promote the development of their self-concept, self-esteem and social skills.

Keywords: Psychosocial development counseling

Title: “HEAR” We Go: Michigan Early Intervention Providers Training Program

Author(s): Angelique Boerst, M.A., Clinical Audiologist 1, Yasmina Bouraoui, M.P.H., Early Hearing Detection and Intervention Coordinator 1, Nancy Peeler, Ed. M., Early On Coordinator for Public Health 1, Lori Van Riper, M.S., Clinical Audiologist 2, Anita Vereb, M.S., Clinical Audiologist 2, Teresa Zwolan, Ph.D., Cochlear Implant Program Director 2

Affiliation(s): 1 Michigan Department of Community Health, 2 University of Michigan Health Systems

Presented by: Yasmina Bouraoui, Nancy Peeler, Anita Vereb

Abstract: Despite no state legislation or mandate, 100% of the birthing hospitals in Michigan provide universal newborn hearing screening. Recent statistics from the Michigan EHDI Program revealed that hospitals voluntarily screen >94% of babies per year. The percentage of babies being screened has shown definite improvement over the years; however, challenges continue when trying to move from a referred screening to diagnosed hearing loss to prompt enrollment in early intervention services. Data indicates that only half of infants diagnosed with hearing loss are enrolled in Early Intervention programs by the time they are six months of age (ASHA, 2005). We know the decisions made for a child with hearing loss in the EI process will profoundly affect the child for his/her lifetime as far as their ability to communicate with others, educational placement, academic performance and role in society as an adult. The objective of this presentation is to provide an overview of a statewide training workshop for early intervention providers called “HEAR” We Go. Representatives from Michigan Department of Community Health, Michigan Early On as well as the University of Michigan Sound Support Program collaborated on this project merging EHDI, Early On, and Audiology resources in order to create a comprehensive statewide training program. The goal of the regional workshops was to provide information and resources to early intervention providers on how to better serve families of children with hearing loss. Outcomes and perceived roadblocks from these trainings along with further initiatives for improving services to families and children with hearing loss as a result of these trainings will be discussed.

Keywords: training, early intervention providers, EHDI goals, roadblocks

Title: The New EHDI Screening and follow-up survey

Author(s): John Eichwald

Affiliation(s): Early Hearing Detection and Intervention (EHDI) Team, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC)

Presented by: John Eichwald

Abstract: As part of Healthy People 2010, this nation has established objectives to ensure hearing screening for all newborns before one month of age, diagnostic audiologic evaluation before three months of age for those who do not pass the screening, and enrollment in early intervention services before six months of age for those identified with hearing loss. In collaboration with NIH, the EHDI program at the CDC is the identified source to report on progress towards these Healthy People 2010 EHDI Objectives. Due to the difficulties in obtaining consistent and comparable data, the CDC-EHDI program released a new EHDI survey in January of 2007. This new survey was designed to collect information in a manner that enables more accurate, reliable, and consistent reporting and statistical analysis of data from across state and territorial EHDI jurisdictions. This data collection method will be used from this point forward as the official source to help assess progress towards the Healthy People 2010 EHDI Objectives. As there are considerable methodology and design differences between the previously deployed surveys and this new CDC-EHDI survey, progress towards the national EHDI objectives is being adjusted to correspond with the values of this new survey tool. This session will highlight those differences in the survey methodology and design and discuss possible implications. During this presentation, data from this new survey that summarizes the current status of efforts related to progress towards the National EHDI Goals and Healthy People 2010 Objective 28-11 will be presented. This will include an overview of standard indicators, such as the percentage of newborns screened and the number identified, and an explanation of what these data suggest. In addition, data related to the number of infants not receiving recommended follow-up tests and the potential reasons for this will be discussed.

Keywords:

Title: Assessment of State Early Hearing, and Intervention Programs (EHDI): A Program Operations Evaluation Protocol (RTI)

Author(s): Pam Costa, Lucia Rojas-Smith

Affiliation(s): Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disability, Early Hearing Detection and Intervention

Presented by: Pam Costa, Lucia Rojas-Smith

Abstract:

Keywords:

Title: Newborn Hearing Screening Training Module

Author(s): Randi Winston, Au.D. 1,2, Lylis Olsen, MS, MPH 2, Karen Ditty, Au.D. 2, Terry Foust, Au.D. 2, Diane Sabo, Ph.D. 2, Marlene Hesley 3, LPN, Karen Munoz, Ed.D. 2

Affiliation(s): 1 The EAR Foundation of Arizona, Phoenix, AZ , 2 The National Center for Hearing Assessment and Management, Utah State University, 3 Banner Desert Hospital

Presented by: Randi Winston, Lylis Olsen

Abstract: Although hospital based universal newborn hearing screening programs have been implemented in the majority of hospitals in the country, state EHDI programs and hospitals face the ongoing challenge of ensuring that all screening staff are properly trained and competent. Inadequately trained screening staff jeopardizes the integrity and efficiency of the early identification process. The EAR Foundation of Arizona in collaboration with NCHAM has developed a competency based training module to meet hospital's training needs that will provide a consistent and comprehensive training solution to the high rate of turnover and the need for ongoing quality assurance. Development of standardized materials that can be applied to diverse hospital settings is an important goal. This session will demonstrate the newly developed, multi-media training module.

Keywords: universal newborn hearing screening programs, competency based training curriculum, ongoing quality assurance

Title: False Positive Inpatient Screening and Parental Anxiety

Author(s): Linda D. Goetze 1, Renata Vintila-Hardwick 1, Karl R. White 2, Scott Grosse 3

Affiliation(s): 1 Early Intervention Research Institute, Utah State University, 2 National Center for Hearing Assessment and Management, 3 Centers for Disease Control

Presented by: Linda Goetze

Abstract: Objective: We address concerns raised about the impacts of false positive results of infant hearing screening tests on families.

Relevance: We have conducted surveys of families of infants in Utah who were referred from newborn hearing screening for further testing over three years. Three samples of families were recruited based on whether the infant was referred to and passed an outpatient screen (n = 117), was referred from outpatient screening to diagnostic testing and was either passed (n = 110) or was diagnosed with hearing loss (n = 152). This allows us to examine whether there is lingering anxiety after a baby does not pass inpatient screening tests.

Implications for Policy or Practice: Generally, families in all groups felt moderately supported by hospital staff. Moderate anxiety following the completion of screening was reported by the families in both groups who were referred to diagnostic testing. In comparison, a very low level of anxiety was reported by families who were referred to outpatient testing but whose infants passed. Finally, all groups expressed strong agreement that they were glad that hearing screening had been performed. The findings by screening group suggest that families whose babies have false positive screening results while in the hospital have very little lingering anxiety or dissatisfaction as a result of the outpatient screening test that follows.

Summary: This study indicates a high level of parent satisfaction with newborn hearing screening among families whose children had false positive inpatient screening tests. The most anxiety about the screening process was expressed by families whose babies were ultimately diagnosed with a hearing loss. The results suggest that the affect of an inpatient false positive hearing screening result on later parent anxiety and satisfaction is minimal.

Keywords: Parent satisfaction and anxiety, Effects of false positive screening

Title: Family Conversations: Giving a Jump on Language and Literacy

Author(s): Ann Curry M.Ed., Susan Norton PhD.

Affiliation(s): Children's Hospital & Regional Medical Center

Presented by: Ann Curry, Susan Norton

Abstract: Following confirmation of their baby's hearing loss parents are faced with many challenges including selecting an early intervention program. Too often different communication methodologies (e.g. ASL, Auditory Oral, and Total Communication) are presented to families as distinct and separate options. However, each child with hearing loss and their family has a unique set of strengths and needs. This presentation will describe Family Conversations Early Intervention Program for Infants with Hearing Loss and their Families. This program provides opportunities for families to find the combination of techniques that works best for their child and family. Both visual and auditory means are used to establish clear communication between families and their child and to help the child understand and use the primary language of the home. Instruction is designed to enhance the parent-child relationship and include all family members, as well as support the incorporation of new strategies into everyday life so parents can provide the love and nurturing necessary to raise a child in today's society. Home visits, playgroup, parent support/education, a lending library, sign language instruction, Deaf community/cultural events, literacy kits, and transition services are all provided as part of this program. Visual means of communication (gestures, lip reading, sign language, and/or cued speech) are combined with speech to help children develop their language, speech and listening skills. Use of hearing aids, FM systems, and/or cochlear implants to learn to understand and use spoken language is strongly supported. Families learn to include their child in all family conversations. An emphasis is placed on literacy through materials, modeling, exploration and play. Summary data as well as video examples of individual sessions will be presented. This presentation will help those seeking to provide unbiased information and early intervention services for deaf and hard of hearing infants and their families.

Keywords: Early Intervention, Language, Literacy

Title: Outreach to Physicians with Delta Zeta Project

Author(s): Sondra King, Penny Baker, Constance Block, Susan Wiley

Affiliation(s): Family Advisor, Ohio Universal Newborn Hearing Screening Advisory Committee, Ohio Coordinator for Delta Zeta Sound Beginnings Project, EHDI Project Director, Ohio Department of Health, Ohio AAP Chapter Champion, Cincinnati Children's Hospital Medical Center

Presented by: Constance Block, Sondra King

Abstract: Objective: This presentation will provide a collaborative model for dissemination of information to physicians.

NCHAM developed a community outreach program with a national social sorority, Delta Zeta. Although the initial national project linked Delta Zeta college students with WIC programs, the Ohio Department of Health and the Ohio Delta Zeta chapters collaborated to extend this educational outreach effort to target physicians.

This presentation will discuss the needed preparation and training activities for the sororities, barriers and successes for information dissemination to physicians, and general feedback from the sororities about their experiences in using this model for physician education.

As states continue to identify effective methods of physician education, this project may be one strategy among many to disseminate information on universal newborn hearing screening and the importance of follow-up for children who do not pass their newborn hearing screens.

Using multiple strategies for physician and public awareness regarding the importance of UNHS and follow-up care is important for the success of EHDI. Collaborating with community groups, such as philanthropic sororities may provide a low cost strategy.

Keywords: Educational Outreach to Physicians, Community Collaboration

Title: On The Road Again: How Site Visits Can Improve EHDI Programs

Author(s): Lorie J. Lang, M.A. CCC-A, Debra Behringer, M.S., RN

Affiliation(s): Michigan Department of Community Health EHDI Program

Presented by: Lorie Lang

Abstract: Over the past 11/2 years, all Michigan birthing hospitals have received a visit from an EHDI staff member in collaboration with the metabolic program. Site visits have provided an opportunity for increasing communication between the hospital and the EHDI program to facilitate dissemination of information regarding state guidelines, protocol for screening and mandatory reporting. In addition, pediatric audiology site visits began in the summer of 2006. More in depth review of diagnostic protocols/ equipment are discussed at these visits as well as introductions of local area parents who serve as parent guides in Michigan's Guide-By-Your Side Program. By putting a name to a face, progress is being made in reporting and referrals! Site visit tool for both facility visits will be shared.

Keywords: Site Visit Tool

Title: Is Early Intervention Necessary for All?

Author(s): Mary Jane Sullivan AuD CCC-A 1, 2, Ruth Fox RN, MS 2, Jan Halley OTR 3

Affiliation(s): 1 University of New Hampshire, 2 New Hampshire EHDI Program, 3 N.H. Multi-Sensory through Consultation and Education (MICE) Program

Presented by: Mary Sullivan, Ruth Fox

Abstract: The Joint Committee on Infant Hearing (JCIH) goal of providing early intervention services for all infants identified with hearing loss by 6 months of age is widely supported. The question we plan to address is:

Do all babies with hearing loss, regardless of the degree and type, require direct intervention services? Historically, in New Hampshire, all children between birth and 3 years of age with a diagnosed hearing loss were automatically enrolled in early intervention services. This process continues for many children, however, universal newborn hearing screening has increased the program demands due to the identification of children with milder forms of hearing loss. Given this, adjustments of the traditional service model were necessary. We will present the criteria used to developed New Hampshire's modified early intervention service plan designed for infants with milder degrees of hearing loss. The changes in our traditional early intervention model are based on each child's audiological results and parental requests. We will address the factors which influenced these changes including parental responses and personnel limitations. Additionally, the process of including the diagnosing audiologists in the intervention planning will be discussed.

Keywords: Parental Input, Professional Collaboration

Title: What is Audism

Author(s): Beth Benedict, Ph.D. 1,2, Barbara Raimondo, J.D. 2

Affiliation(s): 1 Gallaudet University, 2 American Society for Deaf Children

Presented by: Barbara Raimondo and Beth Benedict

Abstract: Most individuals are not familiar with the term “audism,” which is just coming into popular use. The definition of audism will be introduced, and a clip of the forthcoming movie, “Audism Unveiled,” will be shown. In this film deaf adults convey their experiences with communication throughout their lives. An audience discussion will follow.

What is audism? How does it impact the family and educational life of a deaf or hard of hearing child? What should professionals know about audism?

Be prepared to have a frank and open discussion about this controversial topic.

Keywords: Audism, families, professionals, deaf community

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, Leanne 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, Leanne 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. Saarlax, Alan R. Hinman, James Mootrey, Karen Torghelle

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

Title: Tympanometry Protocols Used by U.S. Early Intervention Audiologists

Author(s): Wendy D. Hanks, Molly A. Kinder

Affiliation(s): Gallaudet University, Washington, D.C.

Presented by: Wendy Hanks

Abstract: Middle ear effusion (MEE) is a common problem in infants and toddlers. The problem may begin at birth with amniotic fluid still present in the middle ear. Infants in the NICU are at increased risk for MEE. Massive amounts of literature are available the diagnosis of MEE using tympanometry in children, but a small amount of literature addresses the tympanometric assessment of MEE in infants between birth and 6 months. Now that it has been recommended that 1000 Hz tympanometry be used for infants under 6 months of age, how is it being utilized in EHDI programs? What norms are being used? What pump speed is best? Are there equipment differences? This session will discuss the results of a survey on tympanometry protocols completed by audiologists serving children from birth to three years. The survey consisted of 25 multi-part questions. Seven questions concerned demographics, 14 questioned typical tympanometry procedures, 2 addressed normative data employed, 1 asked where information on 1000 Hz tympanometry was obtained, and 1 question asked if the respondents would like a copy of the summary data. Requests to complete the survey were sent via email to three list serves: U.S. EHDI Coordinators, Educational Audiology Association, and Sound-Off of the American Academy of Audiology. After this request, 153 audiologists completed the survey online. SurveyMonkey was used to present the survey and gather the data online. No identifying information was obtained. From these data: 1) trends will be discussed, 2) recommendations will be made for the development of formal tympanometry protocols for children aged birth to three, and 3) suggestions for further research will be proposed.

Keywords: tympanometry, audiological assessment, audiological protocols, otitis media, middle ear effusion

Title: Monitoring Risk Factors for Late-Onset Hearing Loss

Author(s): Richard C. Folsom, Ph.D. 1, Susan J. Norton, Ph.D.1, 2, Esther Ehrmann, B.S. 2, Richard Masse, MPH 3

Affiliation(s): 1 University of Washington, 2 Children's Hospital & Regional Medical Center, 3 Washington State Department of Health

Presented by: Susan Norton

Abstract: In 2004, the Association of University Centers on Disabilities funded a three-year project to investigate the feasibility of monitoring infants with risk factors for late-onset or progressive hearing loss. The project is now in year 3 and this presentation describes progress to date. JCIH (2000) recommended that at-risk infants should be tracked and assessed for hearing sensitivity on a periodic basis. In light of the proposed changes to the position statement in 2006, this grant uses the JCIH Risk Indicators for Hearing Loss, which continue to be a valuable resource for the ongoing surveillance of infants and young children who require monitoring. In addition, this grant provides education of hearing screening personnel, audiologists, and primary care physicians across the state of Washington. This educational effort is an integral part of determining the associated costs and resources required to track children for late-onset hearing loss. An infant tracking and surveillance system developed through the Centers for Disease Control and Prevention is currently being used to track all infants screened in Washington State. The Washington State Early Hearing Loss Detection, Diagnosis, and Intervention (EHDDI) program has been tracking an increasing number of infants screened for hearing loss in Washington since 2002. Approximately 65,000 infants in 2005, and an estimated 76,000 infants in 2006 will have had hearing screening and been coded for risk indicators in addition to hearing screening, demographic, and diagnostic follow-up data. Data collected to date indicate a significant incidence of hearing loss in infants who pass their newborn hearing screen. Successful follow-up of infants with risk factors for late-onset or progressive hearing loss will be important to the long term success of EHDI programs.

Keywords: late-onset, risk factors, JCIH, ongoing, monitoring

Title: Integrated Medical Care for Children who are Deaf/Hard of Hearing

Author(s): Ellis Arjmand, Susan Wiley

Affiliation(s): Cincinnati Children's Hospital Medical Center

Presented by: Ellis Arjmand, Susan Wiley

Abstract: The medical work-up and management of children with hearing loss includes a number of recommendations and spans a number of specialists. The Joint Committee on Infant Hearing endorses medical, genetic, and ophthalmologic evaluations for children identified with hearing loss. The objective of this presentation is to describe a model of integrated care which facilitates the medical management and evaluation of children with hearing loss.

Since July of 2005, Cincinnati Children's Hospital Medical Center Division of Pediatric Otolaryngology implemented a coordinated approach to scheduling evaluations for children with newly identified hearing loss. Intake information is gathered and children are scheduled for a variety of evaluations which can include Pediatric Ophthalmology, Genetics, Developmental Pediatrics, Pediatric Neurology, Speech/Language Evaluation, Aural Rehabilitation Evaluation, as well as imaging and blood work. These evaluations typically occur over a two week period. The evaluation results are discussed with the family by the managing pediatric otolaryngologist.

This presentation will discuss the development of starting a clinic system such as this as well as provide information about overall utility of evaluations for these children and families.

This coordinated subspecialty model of care has implications for improving the timely and comprehensive completion of appropriate medical work-up for children who are deaf or hard of hearing.

Keywords: care coordination, medical work-up of children who are deaf/hoh

Title: Parents' Guide to Hearing Loss En Español

Author(s): Claudia Gaffney, MPH, McKing Consultant

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

Presented by: Claudia Gaffney

Abstract: When a baby is diagnosed with hearing loss a large amount of information is required by families to help them provide the best and most appropriate services to their child. While English-speaking parents can obtain information from numerous resources, Spanish-speaking parents appear to have far fewer available resources. In addition, Hispanic families often have to contend with additional issues, such as cultural and language barriers before they can obtain information about the resources and programs available for their children.

To address these issues, CDC's EHDI program, in cooperation with several partners, developed a culturally sensitive educational tool in Spanish for families of children with hearing loss called Guía para familias de niños con pérdida auditiva. This product, designed specifically for Spanish speaking families, is culturally and linguistically appropriate and is based on formative research. This presentation will provide an overview on how this product was created and how it is being disseminated. This information should be helpful for state EHDI programs interested in developing educational materials for hard-to-reach populations.

Keywords: Minorities, Educational materials, Diversity

Title: Children with Hearing Loss and Syndromes

Author(s): Gale Rice, Susan Lenihan

Affiliation(s): Fontbonne University

Presented by: Gale Rice, Susan Lenihan

Abstract: This presentation will address prevention, identification and remediation of speech, language and learning characteristics of children who are deaf and have syndromes. Family support and guidance will also be included in the presentation. The presence of a syndrome in a child with a hearing loss can have a major impact on speech, language and literacy learning. The impact of these syndrome-related difficulties may also have a significant effect on families. Recent research indicates that 40% of children who are deaf/hard-of-hearing have additional “concerns” and that one-third of those have syndromic causes of deafness. While some syndromes are diagnosed at birth, others are not diagnosed until children are older and have already experienced speech, language and learning issues.

It is important for early interventionists to be familiar with speech, language and learning characteristics associated with syndromes. This allows developing a preventative approach to the child and his family rather than a remedial one. It is equally important for the practitioner to recognize orofacial and speech-language characteristics which may be indicative of a syndrome in order to refer the child for further assessment of the possible presence of a syndrome.

This session will familiarize the participant with orofacial, speech, language, and learning characteristics associated with syndromes found in children who are deaf/hard-of-hearing. Prevention, assessment and remediation strategies will also be presented. The use of authentic materials in the natural environment will be emphasized. Approaches and resources for family support and guidance will be presented.

Keywords: Syndromes, orofacial, early intervention, family support

Title: Auditory Dys-Synchrony among Very Low Birth Weight Infants

Author(s): Winnie Chung, Courtney O'Neil, Betty Vohr

Affiliation(s): Rhode Island Hearing Assessment Program, Women & Infants Hospital

Presented by: Winnie Chung, Courtney O'Neil

Abstract: The general diagnostic requirements for auditory dys-synchrony are absent middle-ear (stapedial) muscle reflexes and Wave V in Auditory Brainstem Response (ABR) but with the presence of otoacoustic emission and cochlear microphonic in ABR. The clinical findings in children with auditory dys-synchrony are variable. Some also have other neurologic findings. The pure tone audiometric result can be variable too, ranging from normal hearing to significantly impaired hearing. In older children speech understanding is poorer as compare with the pure tone test result. Infants who are at risk are those who require care in the NICU and who have neurologic findings and hyperbilirubinemia.

The objective of this study is to identify the rate of Auditory Dys-Synchrony in the NICU (Neonatal Intensive Care Unit) with the implementation of a new protocol for all infants with birth weight less than 1500gm. All infants less than 1500gm will be screened with TOAE (Transient Otoacoustic Emission) & AABR (Automated Auditory Brainstem Response). Data will be reported on the first 100 infants who have completed the protocol. The following data will be reported:

Total number of infants <1500gm screened.

Incidence of auditory dys-synchrony in infants <1500gm.

Incidence of hearing loss in infants <1500gm.

Risk factors of the small cohort of infants who have auditory dys-synchrony.

Keywords: Auditory Dys-Synchrony

Title: Language: Impact of Degree of Hearing Loss and “Very Early” EI

Author(s): Betty Vohr 1, Julie A. Jodoin-Krauzyk 1, Richard Tucker 1, Mary Jane Johnson 2, Deborah Topol 2

Affiliation(s): 1 Rhode Island Hearing Assessment Program at Women & Infants’ Hospital, Providence, RI; 2 Family Guidance Program at the Rhode Island School for the Deaf, Providence, RI

Presented by: Betty Vohr, Julie Jodoin-Krauzyk

Abstract: Children with permanent hearing loss (HL) and controls born between 10/15/02 and 1/31/05 were enrolled in a prospective study of child language outcomes. The objective was to determine the language outcomes of children with minimal/mild (Min) HL (unilateral or bilateral HL \leq 40 dB) and moderate-to-profound (Mod) HL (bilateral HL $>$ 40 dB) compared to hearing control children at 12-16 months of age and to examine the effects of “very early” enrollment (\leq 3 months) in early intervention (EI). Child language was assessed in 30 children with HL and 96 controls. Eighteen children had Mod HL and 12 children had Min HL. The MacArthur-Bates’ Communicative Development Inventory: Words & Gestures was administered to mothers. The children in the Mod HL group had lower scores for phrases understood, early gestures, late gestures, total gestures, and words produced, compared to the children with Min HL and control children. In addition, children with HL enrolled in EI \leq 3 months versus $>$ 3 months had a significantly greater number of phrases understood, words understood, and words produced. Regression models to test the effects of age of entrance into EI on language for children with HL identified Mod HL and EI \leq 3 months as independent predictors of words produced. Discussion will include a complete description of demographics, maternal and child characteristics, language outcomes, and regression analyses to predict language.

Keywords: hearing loss, early intervention, language development

Title: Where Families Find Support

Author(s): Janet DesGeorges, Outreach Director 1, Kathleen Watts, MA, Director of Training and Technical Assistance 2

Affiliation(s): 1 Hands and Voices National, 2 National Center for Hearing Assessment and Management

Presented by: Janet DesGeorges, Kathleen Watts

Abstract: As Early Hearing Detection and Intervention programs have evolved, so has the need for support for the families of children identified with hearing loss. Most states/territories have developed written materials to provide parents with the information they will need to address the special needs of a child who is deaf or hard of hearing. Some states have additional services available for families. Few states have developed a comprehensive approach to family support. This presentation will provide the material covered at the Investing in Family Support meeting held in September, 2006. The presentation is designed specifically for those states unable to attend the meeting.

After attending the presentation, participants will be able to describe a comprehensive model for family support, list resources available to assist in the development of a comprehensive program and identify the strengths and weaknesses of the family support system within their state.

Keywords: Family Support

Title: Choices in Genetics: The Parent Perspective on Genetics Testing in EHDI Systems

Author(s): Janet DesGeorges 1, Molly Martzke 2

Affiliation(s): 1 Colorado Families for Hands & Voices, 2 Wisconsin Hands & Voices

Presented by: Janet DesGeorges, Molly Martzke

Abstract: When it comes to making choices for children who are deaf or hard of hearing, families are faced with many considerations in the decision making process. The decision to seek Genetic testing and counseling is one of those issues in which families need good information and support to make effective choices. As the ongoing implementation of EHDI systems and state & national guidelines continues throughout the nation, the importance of continuing to 'hear the voice of the parent' in what recommendations are given to families is essential. This presentation will give recent research and survey results from various sources about what families are saying about Genetics testing, why some families choose genetics testing and others do not, and what challenges and barriers still exist in ensuring continuity of care for all families.

Keywords: Genetics, Parent Choice, EHDI Systems

Title: OAE Hearing Screening in Primary HealthCare Settings: What are we finding?

Author(s): Randi Winston, Au.D

Affiliation(s): 1 The EAR Foundation of Arizona, Phoenix, AZ, 2 The National Center for Hearing Assessment and Management

Presented by: Randi Winston

Abstract: Two years ago, a pilot project was launched to demonstrate the efficacy and feasibility of conducting OAE hearing screening, in Primary Healthcare settings as part of a child's well child check. The project objectives were to plan, develop and implement hearing screening programs for children ages birth to three. The project included the use of handheld OAE equipment, training materials and protocols. Three primary health care settings were selected for participation; two large urban community health clinics and one pediatric private practice. Over the course of a year, programs were closely observed and monitored, information and feedback was gathered and screening data was collected. Additionally, a review of medical charts was conducted which provided valuable insights as to how recommended screening protocols were being followed and whether children were being appropriately referred as a result of the screening. This session will include a discussion of the findings as well as a case study related to the screening protocol. Participants will have an opportunity to consider benefits, difficulties and challenges learned and factors that might influence the outcome.

Keywords: OAE hearing screening, Primary Healthcare settings, Well Child Check, Screening Protocols, Data

Title: ECHO's of EHDI: How periodic early childhood screening is growing

Author(s): William Eiserman, Ph.D., Randy Winston, Au.D., Lenore Shisler, M.S., Jan Buhrmann, Ph.D., Terry Foust, Au.D.

Affiliation(s): National Center for Hearing Assessment and Management, Utah State University

Presented by: William Eiserman, Ph.D., Randy Winston, Au.D., Terry Foust, Au.D., and state representatives such as Kim Sykes (KS), Karen Munoz (IL), Jeff Hoffman (NE), Jennifer Hart (MI), Vicki Thomson (CO), Patti Martin (AR), Marcia Fort (North Carolina)

Abstract: The groundwork laid by state EHDI coordinators in implementing Universal Newborn Hearing Screening is creating momentum toward periodic screening of children 0 - 3 years of age. Currently, at least 10 states are making concerted efforts to improve the availability of quality, periodic hearing screening for young children. EHDI Program Coordinators and other key state representatives spearheading this work will review activities underway in their states where EHDIs are actively partnering with other state programs, hospitals, Schools for the Deaf, early childhood programs such as Head Start, early intervention programs, and health care clinics to improve hearing screening and follow-up for young children. This presentation will review the steps necessary to establish periodic screening activities in different settings, resources needed to do so, processes and materials for training and supporting those providing screening and follow-up services, and appropriate protocols that are being followed. Outcome data on more than 4000 birth to three-year-old children who were screened after the newborn period will be reviewed along with a discussion on how outcome data can be used to monitor newly established programs as well as help address lost-to-follow-up concerns of EHDI programs. Specific models will be presented on how creating "new" state partnerships has the potential for closing the gap between newborn and school-age hearing screening.

Keywords:

Title: Not The News You Were Hoping to Hear: Your Child Has Hearing Loss

Author(s): Meredith Isola

Affiliation(s): 1 Parent of a child with mild to moderate hearing loss, 2 Vice President, Ogilvy Public Relations Worldwide

Presented by: Meredith Isola

Abstract: Being told your child has a hearing loss is one of the most devastating things a parent can hear. It is difficult to understand, to accept and to explain to others, but it can also become your cause. As a mother of an 18-month old with mild to moderate hearing loss, I will share my personal experiences dealing with my son, how his hearing loss has impacted our family and how I have committed myself to educating others about early childhood hearing loss. I remember how alone and overwhelmed we felt when we first learned of William's hearing loss. It was tremendously helpful to connect with and talk to other parents of children with hearing loss, particularly the same level of hearing loss, about how to deal with it all. Having parents share personal stories can help new parents to better understand, accept and eventually advocate for their children. Some of the most important insight we have gained in this journey has been from other parents. This presentation will take attendees through our journey, from the time William failed his newborn screening, to his diagnosis, up until now. It will discuss some of the issues we've had to deal with including motor delay, understanding and explaining to others the difference between mild to moderate loss and other levels of hearing loss, and will also discuss significant milestones in our journey including our positive experiences with auditory verbal therapy. It is the hope that at the conclusion of the presentation, attendees walk away with a better understanding of one family's experience navigating what can be a complex, overwhelming and emotional process. It is also the hope that attendees, particularly parents of children, feel they are able to relate to the presentation and/or that they can learn from my family's experience.

Keywords: Parent; Personal Experience

Title: Two Implants: The Good, the Bad, and the Ugly

Author(s): Taunya Paxton

Affiliation(s): A Parent

Presented by: Taunya Paxton

Abstract: This session will feature the mother of a 6-year-old child who recently received bilateral cochlear implants. She will discuss her experience in coming to the decision for the first implant, and then four months later, the second implant. She will discuss the progress she has seen in her son after the first, then after the second implant. She hopes to help professionals understand the parents' perspectives in the cochlear implant decision making process. Also, she plans to give an honest critique of having two cochlear implants: the successes, the limitations and what was learned along the way.

Keywords: parent experience, bilateral cochlear implant

Title: Women's Knowledge of Congenital Cytomegalovirus (CMV): Baseline Information

Author(s): Danielle S. Ross, PhD, MSc, Esther Sumartojo, PhD, MSc, Marcia Victor, MPH, Michael J. Cannon, PhD.

Affiliation(s): Centers for Disease Control and Prevention

Presented by: Danielle Ross

Abstract: What do women know about congenital CMV and what are they willing to do to prevent infection? Congenital cytomegalovirus (CMV) infection can cause temporary symptoms and permanent disabilities such as hearing loss and mental retardation. A common way pregnant women are infected with CMV is by exposure to toddlers following their first (usually asymptomatic) infection. Although there are currently no vaccines available for preventing congenital CMV infection, transmission can be prevented through hygiene.

We submitted 4 questions to HealthStyles™, an annual mail survey sent to a large sample of adults in the United States. The questions asked whether women had heard of CMV, where they had heard of it, what they knew about its effects, and what they would be willing to do to prevent congenital infection.

Only 14% of women knew about CMV. Trend analyses revealed an increase in education level and household income ($P < .001$) were associated with an increase in the percentage of women who had heard of CMV. Age, race/ethnicity, and geographic region were not associated with such differences. With the knowledge that an infection could hurt their unborn child, most women (97%) said they would find it easy to wash their hands after changing a child's diaper and avoid sharing utensils with young children (86%). Most women said they would find it easy to avoid kissing a young child on the mouth (68%), although a large minority (31%) would find it difficult. The more difficult the behavior was rated, the more likely it was influenced by different demographics, pregnancy planning status, and having a child under the age of 5 years.

Education about prevention of congenital CMV is needed. The prevention messages appear to be generally acceptable, although acceptance of some varied by age, race/ethnicity pregnancy status and plans, and presence of young children in the home.

Keywords: CMV, cytomegalovirus, congenital cytomegalovirus, congenital infection, prevention

Title: Screening for Congenital Cytomegalovirus (CMV) Infection and Hearing Loss as an Adjunct to EHDI Programs

Author(s): Scott D. Grosse 1, Danielle S. Ross 1, Sheila Dollard 2

Affiliation(s): 1 National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA; 2 National Center for Immunization and Respiratory Diseases, Centers for Disease Control and Prevention, Atlanta, GA

Presented by: Scott Grosse, Danielle Ross

Abstract: Congenital cytomegalovirus (CMV) infection is a leading cause of hearing loss in children, especially late-onset, progressive, or fluctuating hearing losses. Most children with infections are asymptomatic at birth, and at least half of those who will develop hearing loss do not have a hearing loss detectable at birth. Consequently, newborn screening for CMV is a potentially important extension of EHDI programs. At present, a reliable, accurate, screening test using dried blood spot specimens does not exist, although development of such a test is in progress. This analysis projects the number and fraction of additional cases of permanent bilateral hearing loss that could potentially be detected by screening for CMV as a complement to universal newborn hearing screening. Assuming that 0.65% of infants in the United States are born with congenital CMV, approximately 4,000 infants will develop permanent hearing loss by school age due to CMV. Further, we estimate that 1,200 to 1,500, will develop permanent bilateral hearing loss of 40 dB or greater in the better ear, comprising approximately 20% of all children with hearing loss and a larger percentage of those with late-onset or progressive hearing losses. In order to identify children with hearing losses in a timely fashion and provide appropriate intervention services, screening of infants for congenital CMV at birth could provide an invaluable adjunct to EHDI programs once a screening test that is feasible for routine public health use becomes available.

Keywords: congenital CMV, etiology, newborn screening, epidemiology

Title: WCSWeb Hearing Link: Data System and User Training Protocol

Author(s): Marcia Fort, Kathy Gajan, Jason Guetgemann, Jerry Ramsey

Affiliation(s):

Presented by: Marcia Fort, Jason Guetgemann

Abstract: Tracking, follow-up, and data management continue to be significant challenges for Early Hearing Detection and Intervention (EHDI) programs. Data systems need to include mechanisms for reporting results as well as maintaining up-to-date information on those children requiring follow-up care. However, these data systems must also remain HIPPA compliant. There are numerous challenges faced by EHDI programs as they attempt to develop new data tracking systems or enhance existing data systems. WCSWeb Hearing Link is a web-based application designed to collect data regarding hearing screening results for all newborns and follow-up information for children who did not pass the initial hearing screening. It includes mechanisms for tracking of risk factors and late-onset hearing loss. The system is available to birthing facilities, midwives, physician offices, and audiologists who may be involved in hearing screening or follow-up services for children in North Carolina. North Carolina EHDI Program Staff provide formal training to all facilities using WCSWeb Hearing Link. This formal training includes hands-on practice with the data system. The use of a standardized training protocol reduces errors in data reporting. Improved data reporting reduces the amount of time required to track missing results and increases the percentage of infants meeting the EHDI 1-3-6 goals. This session will provide a demonstration of WCSWeb Hearing Link, a discussion of the challenges faced during development of a new data system, and a description of the formal training protocol used.

Objectives: (1) Identify key components of EHDI data tracking systems; (2) Outline challenges of data system development/enhancement; (3) Understand importance of formalized training procedures for EHDI data reporting

Keywords: Data Tracking System, Training Protocol

Title: Providing Early Intervention Training in a Local Control State

Author(s): Nancy Hatfield, Amber Roche

Affiliation(s): Washington Sensory Disabilities Services (Puget Sound Educational Service District), Washington State Department of Health Genetic Services Section

Presented by: Nancy Hatfield, Amber Roche

Abstract: Your state may be screening 90%+ of all newborns, but without early intervention services in place for families upon diagnosis of hearing loss, what use is it? Washington is a state with a healthy menu of services in the Seattle-Tacoma metropolitan region, but in many other areas services vary from little to none. Sound like your state? Our goal five years ago was to devise a training plan to develop skills of local service providers so that they are better qualified to support infants and toddlers with hearing loss through family-centered services. Our challenge has been to accomplish this in a state with a tradition of local control, with funding allocated to county-level agencies and local school districts.

This presentation will summarize our inter-agency efforts to strengthen skills of service providers and share lessons learned from our current vantage point. With the support of funding from the Health Resources Services Administration (HRSA) via our Department of Health, our lead Part C agency (the Infant-Toddler Early Intervention Program), and in-kind contributions from our state education agency and local providers, we developed a four-year plan that targeted several counties each year for intensive training and on-site technical assistance and coaching. We collaborated with counties much like we work with families, building relationships and developing individualized county plans. We will describe: (1) our underlying philosophy; (2) the content and methods selected for instruction, including distance education; and (3) contrasting case stories from several counties. We will summarize results to date based on participants' self assessments of their knowledge and skill attainment and the impact on the families with whom they work—including the outcome of reducing loss to follow up.

Keywords: Early intervention, training

Title: Parent to Parent Support: A Guide to Making Connections

Author(s): Cheri Dowling 3,4,5,6,7,8,9, Patricia Timm, MEd. 1,2,3,4

Affiliation(s): 1 CAID, 2 CED, 3 Maryland State Department of Education Family Support Network, 4 Maryland School for the Deaf, 5 Maryland State Steering Committee for Parent to Parent Support, 6 Maryland Universal Newborn Hearing Screening Council, Parent Representative, 7 Connections Beyond Sight and Sound Advisory Council, 8 Maryland School for the Deaf, Parent Teacher Counselor Association, President, 9 American Society for Deaf Children

Presented by: Cheri Dowling, Patricia Timm

Abstract: When a family discovers their child has a disability, they may have feelings of isolation, and may begin to search for help, support and possibly guidance. Support from another parent of a child with a disability may enable the new parent to better understand and accept their own child's disability. This interactive presentation will demonstrate how to form both formal and informal Parent to Parent support groups. Discussion will support the importance of why groups should be formed, how and where to start them and why these groups should be parent led. Participants will also learn simple strategies to use to teach parents how to offer support and understanding in a non-bias way. Participants will learn the importance of confidentiality within the group. Collaboration will be discussed and participants will learn strategies to use to collaborate with other groups and organizations in their area. All participants will leave the session with a complete guide, including sample forms and procedures, to starting a parent to parent support group in their area.

Keywords: Parent to Parent Support

Title: Step into the Void: Vestibular Deficits in Children with Hearing Loss

Author(s): Genevieve DelRosario, MHS, PA-C

Affiliation(s): Department of Pediatrics, University of Kansas Medical Center

Presented by: Genevieve DelRosario

Abstract: Vestibular deficits are known to occur in a significant percentage of deaf and hard of hearing children. Despite this, information regarding identification and treatment of these balance issues remains very poorly understood, particularly in infants and very young children (under age five). This failure to identify vestibular dysfunction in very young children may have significant detrimental effects, ranging from misdiagnoses and costly, invasive medical tests to a failure to offer appropriate intervention.

This presentation will offer an overview of vestibular deficits in very young children with a particular emphasis on identification, treatment, and opportunities for future research. Greater dissemination of this information should allow infants and children to be directed more quickly to appropriate care, allowing for optimal motor development while minimizing familial concerns.

The objectives of this presentation are:

At the conclusion of this presentation, attendees should feel confident in their ability to determine if a deaf/hard of hearing child has significant vestibular pathology.

At the conclusion of this presentation, attendees should feel confident in their ability to formulate a plan to improve the quality of life for deaf/hard of hearing children with balance deficits.

At the conclusion of this presentation, attendees will have a general understanding of current knowledge regarding vestibular dysfunction, as well as the limitations of that knowledge.

Keywords: vestibular deficits, balance, early intervention

Title: Effects of Federal and State Privacy Laws on 1-3-6 Month Service Delivery Goals

Author(s): Gary Mears, Ed.D. 1, Edward Burke, M.Ed. 2, Mark Rothstein, J.D. 3

Affiliation(s): 1 Information Ventures, Inc., Philadelphia, PA, 2 International Consultant, Warrenton, VA, 3 Institute for Bioethics, Health Policy and Law, University of Louisville, Louisville, KY

Presented by: Gary Mears

Abstract: In recent years, national recommendations for early hearing screening and intervention for infants with hearing loss have been established. For example, the Joint Committee on Infant Hearing, and the American Academy of Pediatrics Task Force on Newborn and Infant Hearing, have endorsed the goals of universal detection of infant hearing loss before one month of age, appropriate audiologic and medical evaluations regarding the presence of hearing loss before 3 months of age, and the provision of intervention services by 6 months of age. Unfortunately, guiding and tracking newborns through the process of detection, evaluation, and intervention has been problematic for many states. The effects that Federal and state privacy laws (including the Health Insurance Portability and Accountability Act-HIPAA, and the Family Education Rights and Privacy Act-FERPA) have on the ability of state newborn hearing screening programs to assess or track follow-up are unclear. This presentation will describe the preliminary findings of a Health Resources and Services Administration (HRSA)-sponsored project to determine how state newborn hearing screening programs have approached the development of HIPAA/FERPA-friendly data systems, and the impact of Federal and state privacy laws on issues related to follow-up and the attainment of the 1-3-6-month service delivery goals. Findings to be presented include: 1) approaches that state newborn hearing screening programs have taken regarding HIPAA, FERPA, and the sharing of health information; 2) an analysis of Federal and state laws governing the sharing of individual health and education information with respect to newborn hearing screening and follow-up; and 3) an analysis of state utilization of birth defects registries and whether such utilization improves capability in reporting hearing loss-related service provision and the attainment of the 1-3-6-month service delivery goals. We anticipate that the presentation will be helpful to state EHDI program personnel with respect to their understanding of the impact of Federal and state privacy laws related to follow-up and the attainment of their 1-3-6-month service delivery goals.

Keywords: follow-up, HIPAA, FERPA, privacy, reporting requirements

Title: Creating Successful Partnerships: A Seamless System for Families

Author(s): Dinah Beams, MA, CED, Lead Colorado Hearing (CO-Hear) Coordinator 1, Stephanie Olson, BA, Deaf Adult Consumer Advisor to the Colorado Home Intervention Program and Parent Mentor at The Childrens Hospital of Denver 2

Affiliation(s): 1 Colorado Home Intervention Program, Colorado School for the Deaf and the Blind, 2 The Childrens Hospital of Denver

Presented by: Dinah Beams, Stephanie Olson

Abstract: One important component of the EDHI system is to move families and children from diagnosis to intervention in a timely manner. In order to accomplish this, partnerships must be formed between all of the players at the various levels of the system and between professionals in the public and the private sector. The success of this collaboration will impact the service delivery, timeliness of referrals, data collection, and most importantly, how parents feel about the services received. This presentation will share information regarding how professionals in Colorado have worked to establish these collaborative relationships, as demonstrated by the presenters. The importance of collaborative relationships between stakeholders, including deaf adults, parents and professionals will also be explored.

Keywords: collaboration, intervention, system building, data

Title: Effective Family Support Communication Strategies

Author(s): Candace Lindow-Davies 1, Karen Putz 2

Affiliation(s): 1 Family Support Coordinator, Family Support Connection/Lifetrack Resources/Minnesota Hands & Voices, 2 Director, Illinois Hands & Voices and Board Member, National Hands & Voices

Presented by: Candace Lindlow-Davies

Abstract: Creation of alternate communication strategies are necessary to reach families with children who are deaf and hard of hearing who already have many demands on their time and often are not able to attend traditional in-person educational workshops. To increase awareness of support issues and resources among family members, the Family Support Connection at Lifetrack Resources/Minnesota Hands & Voices has developed multiple communication tools over the past 6 years. This presentation will describe the various methods created by this parent-to-parent support program to effectively reach over 700 families and the professionals who work with them. The communication vehicles discussed will include: an informative monthly newsletter disseminated by mail, email, web site posting, and a shorter “school flyer” version distributed by school districts; a unique database system designed to merge client data with a email system capable of mass emailing constituents by interest group and electronically filing incoming client messages; a series of “Parent Welcome” letters written by veteran parents directed at families of newly diagnosed children in an effort to encourage parent-to-parent support (several letters are in Hmong, Spanish, and Somali languages); fact sheets; educational workshops; social events; retreats; and regional family activities. Another important new resource shared will be National Hands & Voices’ web-based bulletin board for families across the country to access in order to post questions and view responses. Individuals can select to post questions for discussion by their state of residence or by topic. A moderator oversees the dialogue to ensure participants respect the diverse choices of families supported by Hands & Voices. By attending this session, participants will be able to return to their own states to implement similar communication methods to more effectively reach and maintain contact with families.

Keywords: web-based, family support, newsletter, bulletin board, information dissemination

Title: Delivering Screening Results: What Parents Want

Author(s): Janet DesGeorges 1, Cami Geilenfeldt 2

Affiliation(s): 1 Colorado Families for Hands & Voices, Hands & Voices National, 2 Iowa Hands & Voices

Presented by: Janet DesGeorges, Cami Geilenfeldt

Abstract: This session covers information about the perspectives and stories of parents who have been through the newborn hearing screening process in hospitals all over the country. Included is a 'wish list' that parents have spoken about what they want during the screening in the hospital, including the types of information they desire and when and how it should be delivered to them. Information from state/national surveys and research data will be presented, as well as the life experience of the two parent presenters. Home Birth issues, and cultural competence considerations will also be explored

Keywords: Newborn Hearing Screening, Parent Choice, Home Birth

Title: Meeting the EHDI Challenge: Strategies for Accurate Reporting

Author(s): Mary Catherine Hess 1, Michael Berry 2

Affiliation(s): 1 Rhode Island Hearing Assessment Program, Women & Infants Hospital, 2 HLN Consulting

Presented by: Mary Hess, Michael Berry

Abstract: Defining categories for newborn screening and follow-up data is an ever evolving process as programs attempt to produce summary data that will be aligned with the missions of local and national public health organizations. Varying protocols by nursery, unique screening scenarios for children with risk factors, screening technology challenges, and public health reporting needs all contribute to the sometimes nebulous and time-consuming task of “fitting” children into pre-defined categories.

The Rhode Island Hearing Assessment Program (RIHAP) uses a data management system called RITRACK and the statewide child health information system KIDSNET to assist with the tracking, follow-up, outreach, and reporting of newborn hearing screening data. After many years of analyzing the data collection systems, reviewing the data elements recommended by the CDC’s Data Committee and the vast array of screening and follow-up scenarios that arise, RIHAP has attempted to document and account for *ALL* the possible screening and follow-up data items that are requested for reporting. Regardless, issues still arise as some children do not easily “fit” the definitions for reporting.

This presentation will review Rhode Island’s hearing screening and follow-up protocols, mechanisms for capturing data, and the algorithms used for calculating the screening and follow-up data that fit the data definitions as defined by such agencies as JCIH, CDC, DSHPSHWA, and the State of Rhode Island. Case studies will be reviewed that will reflect typical and challenging reporting situations. In addition, the audience will be prompted to share their own solutions for data reporting.

Keywords: EHDI, Data, Rhode Island, Reporting, DSHPSHWA

Title: An Evaluation of the NC EHDI Program—What We're Learning

Author(s): Joni Alberg, Ph.D. 1, Christene Tashjian, MPA 1, Jackson Roush, Ph.D. 2, and Kathryn Wilson, MA, CCC-SLP, Cert. AVT 3

Affiliation(s): 1 BEGINNINGS For Parents of Children Who Are Deaf or Hard of Hearing, Inc., Raleigh, NC, 2 University of North Carolina at Chapel Hill, 3 Office of Education Services, NC Department of Health and Human Services, Raleigh, NC.

Presented by: Joni Alberg, Christene Tashjian, Kathryn Wilson

Abstract: In April 2005, the North Carolina Department of Health and Human Services' Office of Education Services and BEGINNINGS for Parents of Children Who Are Deaf or Hard of Hearing, Inc. began a longitudinal study to determine how well NC is meeting the goals of newborn hearing screening and early intervention for children who are deaf or hard of hearing. A Pilot Study was conducted to test subject selection strategies, data collection instruments and study procedures. During the Pilot Study, data were collected about the age of children at initial hearing screen, re-screen, diagnosis, and initiation of early intervention; screening and diagnostic instruments used; type of hearing loss; family information; other health challenges; frequency and extent of early intervention; parental involvement in early intervention; and language outcomes (expressive and receptive) at time of transition from early intervention. Plans are to follow these children until they reach Kindergarten, administering the Preschool Language Scale, Fourth Edition (PLS-4) to each child annually throughout their preschool years to determine progress in language as measured by the PLS-4. Data from the PLS-4 assessment for a sample of 4 year olds will be included.

Children for whom data have been collected met these criteria: born since newborn hearing screening was enacted in NC, have been served by BEGINNINGS, and received services from the NC Early Intervention Program for Children Who Are Deaf and Hard of Hearing. As of September 15, 2006, 106 families have agreed to participate in the study.

During this presentation, we will explain how the study was designed and share the preliminary findings of the Pilot Study.

Keywords: evaluation, child and program outcomes

Title: Cochlear Implants and the Early Intervention Team

Author(s): Karen Clark, M.A. 1, 2, Antonia Brancia Maxon, Ph.D. 1, 3

Affiliation(s): 1 National Center for Hearing Assistance and Management, Logan, UT, 2 UTD/Callier Center for Communication Disorders, Dallas, TX, 3 New England Center for Hearing Rehabilitation, Hampton, CT

Presented by: Karen Clark, Antonia Brancia Maxon

Abstract: Increasingly, early interventionists are serving families of older infants and toddlers who have cochlear implants. Successful early intervention requires the combined effort of all members of the team and is enhanced when all members have a basic understanding of implant technology and the importance of listening and talking throughout the child's day. The purpose of this presentation is to provide an overview of auditory strategies that can be used within home and/or center-based settings to increase auditory emphasis for the child. The importance of ongoing mapping (programming) of the speech processor will be emphasized. Ways in which the early intervention professionals and family members can determine how well the baby is hearing and effectively convey that information to the mapping audiologist will be emphasized. Strategies will include intervention and documentation ideas that are adaptable to both auditory only and total communication environments. Also included will be suggestions for supporting the knowledge base of early interventionists who have limited experience in auditory learning or cochlear implants and for supporting families in monolingual Spanish homes.

Keywords: cochlear implant, auditory learning, mapping, early intervention

Title: Serving Children With Cochlear Implants: Connecting Providers

Author(s): Kelli Halter 1, Sandra Brotman Domoracki 2

Affiliation(s): 1 Project Director, Regional Infant Hearing Program, Regions V & X, Cleveland Hearing and Speech Center, 2 Project Director, Regional Infant Hearing Program, Region IX, Family Child Learning Center, Department of Akron Children's Hospital and in affiliation with Kent State University

Presented by: Kelli Halter, Sandra Brotman Domoracki

Abstract: Ohio Department of Health has funded ten Regional Infant Hearing Programs (RIHPs) to assure that families with children (0-3) diagnosed with hearing loss are provided appropriate habilitative services by a parent advisor through regular home visits. A component of the habilitative program and responsibility of the RIHP parent advisor is to actively participate in outreach efforts designed to enhance awareness and interaction between families and providers, and to provide outreach to professionals to broaden each family's access to support and services. Outreach includes open transfer of communication among team members to best serve the family/child. A need identified in research, and one we encountered in our services, is the development of communication among providers for children with cochlear implant(s).

Each region of RIHP has worked to develop connections among providers in their geographical area. It was necessary, therefore, to build connections with providers for families whose children have cochlear implant(s). Two northeastern regional programs in RIHP, working with the areas' cochlear implant teams, facilitated a meeting with all involved professionals to begin a forum for continued dialogue. The initial meeting allowed for all parties to meet, discuss ways to improve communication among agencies, and create strategies to support and provide the resources necessary to accommodate children with implants in early intervention and schools.

This presentation will review the planning, networking, and preparation that led up to the initial meeting, how participants succeeded in brainstorming; what works and what doesn't work, and the action steps the group developed. We will share how the conclusion of the initial meeting was really the beginning of an ongoing process. We will offer examples of our successes and challenges, what we would do differently, and our plans for the future.

Keywords: Cochlear implants, family, team, communication

Title: Early Intervention of Children Identified with Auditory Neuropathy

Author(s): Karen Markuson Ditty, AuD 1, 2, Sharon Markuson Parham, M.S. 3

Affiliation(s): 1 National Center for Hearing Assessment and Management (NCHAM), 2 Texas ENT Specialists, P.A., 3 Northwest Harris County Cooperative for the Hearing Impaired

Presented by: Karen Ditty, Sharon Parham

Abstract: Over the last decade and more we have learned a great deal about Auditory Neuropathy, and yet there is still much we just do not know. This dilemma makes it difficult to develop individual educational programs for infants identified with this type of hearing disorder. Auditory Neuropathy is often followed closely to see if there is any improvement or worsening over time. Hearing aids may or may not help with this disorder. Educators for the deaf and hard of hearing may receive conflicting information from Audiologists and Parents concerning diagnostic test results. Parents have to make many decisions concerning intervention strategies for their child and are often overwhelmed by the new terminology and sometimes conflicting information they receive. This presentation will discuss clinical assessment and intervention strategies for infants and toddlers identified with Auditory Neuropathy. Intervention strategies will be discussed and recommended based on evidence to date.

Objectives:

Define the audiological diagnostic "indicators" of Auditory Neuropathy.

Identify audiological protocols currently used in the diagnosis of Auditory Neuropathy.

Identify factors that may contribute to parent and interventionists frustration concerning educational planning for children with Auditory Neuropathy.

Identify early intervention strategies for children diagnosed with Auditory Neuropathy.

Keywords: Auditory Neuropathy, Early Intervention

Title: Finding “Lost” EHDI babies: The answer may be right in front of you

Author(s): Felicia Chase Goodman 1, Doug Dittfurth 2 , Chris Watkins 3

Affiliation(s): 1 OZ Systems, 2 Texas Department of Assistive and Rehabilitative Services, Deaf and Hard of Hearing Services (DARS-DHHS); 3 Texas Department of Assistive and Rehabilitative Services, Early Childhood Intervention (DARS-ECI).

Presented by: Felicia Chase Goodman, Doug Dittfurth, Chris Watkins

Abstract: In 2004, Texas reported excellent birth screen coverage. Yet for 47% of babies with suspected hearing loss, no follow-up information was received. Linkages connecting screening with intervention were limited, as was timely referral to Part C. As a HRSA funded effort, we mapped counties for families needing services and designed an approach to capitalize upon existing manpower in those counties. Resource Specialists working for the Texas Department of Assistive and Rehabilitative Services - Office for Deaf and Hard of Hearing Services were called upon to assist with timely follow-up care for babies with suspected hearing loss. Prior to this project, these specialists were advocates for deaf/hard of hearing adults in their communities and were familiar with community providers and stakeholders.

The goal was to use the existing TEHDI information system to connect more babies to services and report results to TEHDI and Part C. To determine the strategies specialists would use, we hosted workshops to solicit user input. Specialized enhancements were designed to track babies who were lost-to-follow-up.

Educational opportunities further enhanced specialists’ skills. Ongoing training opportunities to teach the enhanced system and optional weekly Q&A meetings provided support. Because of previous work and because several specialists are persons with hearing loss, the group had some understanding of issues surrounding hearing loss. Most had little understanding of issues related to newborns with hearing loss. National University online courses on EHDI were made available to enhance their knowledge.

The project’s successes and limitations will be discussed, including benefits and challenges of the educational experience. Follow-up outcomes in 2005 will be compared with 2006.

Participants will learn: (1) HIPAA compliant strategies for linking providers (2) Strategies for increasing the number of infants reaching early intervention by six months of age; (3) Strategies for increasing the number of infants with documented services.

Keywords: EHDI (Early Hearing Detection and Intervention), Part C, information systems

Title: What the Joneses Taught Me

Author(s): Carrie Davenport 1, Barbara Raimondo 2, Marilyn Sass-Lehrer 2

Affiliation(s): 1 Ohio School for the Deaf, 2 Gallaudet University

Presented by: Carrie Davenport, Barbara Raimondo, Marilyn Sass-Lehrer

Abstract: Learning from families is key to the success of EHDI programs.

The Family Centered Early Education (FCEE) graduate program at Gallaudet University prepares students to work with young deaf and hard of hearing children and their families. A requirement of the FCEE program is that students participate in the Family Matching project. Students are matched with families of young deaf and hard of hearing children and spend 30 hours with the family over three semesters. They interact with the family and participate with the family in a variety of typical everyday experiences, such as going on errands, attending medical appointments, and sharing a meal with the family. Students keep a journal of reflections of their experiences. The goal of Family Matching is for the students to learn, from the family's perspective, what it is like to raise a deaf or hard of hearing child. Students often report that the Family Matching experience is one of the most valuable of their Master's program. They value the relationship established with their family and learn lessons that they take with them into their professional lives.

Through this workshop, attendees will 1) understand why it is important to include families in the preparation of professionals and in programs serving deaf and hard of hearing children and their families; 2) become familiar with the components of a Family Matching project; and 3) learn strategies they can use to include families and family perspectives in the preparation or in-service development of professionals and in programs serving deaf and hard of hearing children and their families.

Presenters will be a family education teacher who participated in the Family Matching project as a student, a professor in the FCEE program, and the parent consultant who coordinates the program.

Keywords: Professional development, family, early intervention

Title: NJ Family Learning Day - A Collaborative Approach to Family Support

Author(s): Malia Corde 1, Nancy G. Schneider, M.A. CCC-A 2, Leslie M. Beres-Sochka, M.S. 2

Affiliation(s): 1 New Jersey Statewide Parent to Parent – A Program of the Statewide Parent Advocacy Network (SPAN), 2 New Jersey Department of Health and Senior Services

Presented by: Malia Corde

Abstract: In 2005, a small committee representing State, parent support and educational agencies came together to establish the first statewide “New Jersey Family Learning Day.” The conference served as a forum for parents to gather and share unbiased information on topics related to raising and advocating for their children with hearing loss. The theme of the 2005 event was “Empowering Parents of Children who are Deaf and Hard of Hearing.” Attendance at this conference was exclusively limited to children with hearing loss and their families. Family Learning Day was presented in collaboration with the New Jersey Division of the Deaf and Hard of Hearing; the New Jersey Early Hearing Detection and Intervention Program, New Jersey Statewide Parent to Parent, The College of New Jersey (TCNJ), and the Marie Katzenbach School for the Deaf (MKSD). Exhibitors and conference sponsors, representing a variety of organizations, were available to parents throughout the day. Teaching staff at MKSD and students volunteers from TCNJ’s Department of Special Education provided age-appropriate activities for children enabling parents to gain much needed knowledge by attending workshops without childcare concerns. Conference topics included: Advocating for Your Children’s Rights; Language Development; Technological Advancements; and Transitions in Education. A “Parent Panel” featuring parents of children with hearing loss; who utilize various assistive technologies, communication modalities and educational placements, was presented. Conference speakers included parent support specialists, attorneys, audiologists, educators, assistive listening device specialists, early interventionists, interpreters and representatives from New Jersey Protection and Advocacy and the New Jersey Division of Civil Rights. Positive post-conference feedback has led to Family Learning Day becoming a biennial event to be hosted by specialty educational programs for children with hearing loss located throughout New Jersey. This presentation highlights important features to consider in hosting a collaborative family centered event for families of children with hearing loss.

Keywords: family support, advocacy, parents, collaboration

Title: Hear from the Start, Talk for a Lifetime

Author(s): K. Todd Houston, Ph.D.

Affiliation(s): The Alexander Graham Bell Association for the Deaf and Hard of Hearing

Presented by: Gerri Hanna, Judy Harrison, Gayla Hutsell

Abstract: Due to recent advances in infant hearing screening, intervention and hearing technology, listening and talking is possible for many of the 12,000 children born each year with hearing loss in the United States. In fact, most children who are deaf or hard of hearing can develop spoken language skills comparable to their hearing peers by their fifth birthday when they are identified early and have access to hearing technology and intensive intervention in audition, speech and language (Geers, et.al. 2003). Despite these remarkable advances, the majority of today's parents are not given information about spoken language when their child is identified with a hearing loss. In fact, studies have shown that 60 % of families do not receive any information about spoken language from a representative who is trained on hearing loss when their child is either screened or diagnosed (Prendergast, et.al. 2002) (Hanna, 2003). In a 2006 commissioned study, nearly 70% of mothers and expectant mothers in a blind survey group of 800 indicated that they were not sufficiently informed about spoken language as an option for children with hearing loss. Ninety-eight percent of the women surveyed indicated that they would be inclined to explore the option of spoken language if their child were diagnosed with hearing loss. Considering that 90% of parents of children with hearing loss have normal hearing and use spoken language (Moore 1987), it is not surprising that when parents are informed of the range of communication options, the majority will choose spoken language for their children with hearing loss.

This session will share additional results of the 2006 research study, information regarding a grassroots early identification awareness initiative about spoken language as a viable communication option, and suggestions on how to communicate with pediatricians and other healthcare practitioners about spoken language.

Keywords: parents, options, spoken language

Title: How Accurate are Newborn Hearing Screening Rates?

Author(s): Denise Green; Marcus Gaffney, John Eichwald

Affiliation(s): Centers for Disease Control and Prevention, National Center for Birth Defects and Developmental Disabilities, Early Hearing Detection and Intervention (EHDI) Program

Presented by: Denise Green, Marcus Gaffney

Abstract: Determining accurate rates of newborn hearing screening can help EHDI programs better evaluate the actual number of infants screened for hearing loss as well serving as a quality assurance indicator. To evaluate the accuracy of available screening rates occurrent birth data from the CDC's National Center for Health Statistics (NCHS) was used to recalculate newborn hearing rates for years 2000 – 2004. The NCHS derived rates were then compared to screening rates that were calculated using state reported birth data, which was reported to the Directors of Speech and Hearing Programs in State Health and Welfare Agencies. While the overall difference between annual hearing screening rates calculated using NCHS and state reported birth data were small (i.e., two percent or less), notably larger variations were observed among some individual states. The majority of states with variations had lower NCHS derived screening rates compared to those calculated using state reported birth data, although a few states did have slightly higher screening rates based on the NCHS birth data. Overall, the number of states meeting the Joint Committee for Infant Hearing screening benchmark of 95%, which is a key performance indicator, is less when the NCHS derived screening rates are considered. Possible reasons for these differences, including background about how NCHS and state reported birth data is calculated, and the importance of standardized data reporting will be discussed. In addition, the importance of integration between state data systems in generating accurate statistics will be addressed. This information should assist interested persons in better understanding how to interpret hearing screening rates as well as identifying ways to help ensure the availability of standardized and accurate data.

Keywords: Screening rates, data integration, reporting, quality assurance

Title: CDC Project Management Resources for EHDI Programs

Author(s): Jamie Elliott, MPA 1, John Eichwald, MA FAAA 1, Tom Savel, MD 2, Nicole Fehrenbach, MPP 3, Peggy Joyner, MBA, PMP 3

Affiliation(s): 1 Centers for Disease Control and Prevention (CDC), Early Hearing Detection and Intervention (EHDI), 2 Centers for Disease Control and Prevention, National Center for Public Health Informatics, 3 BearingPoint, Inc. for the National Center for Public Health Informatics

Presented by: Jamie Elliott, John Eichwald

Abstract: Industry research, based on analysis of over 40,000 projects, indicates only 34% of information technology (IT) projects were successful. In response to this challenge, the CDC initiated the development of a clearly defined approach to successful IT project management and delivery, the CDC Unified Process (CDC UP).

The CDC approach utilizes industry leading practices that can be applied to any project, including non-IT, to increase the efficiency and effectiveness of project management practices and processes. These project management tools and resources are easily accessible via the CDC website and include a range of process guides, practice guides, templates, checklists and more. This resource provides valuable tools to identify and plan activities throughout a project's life cycle. Templates are designed to be customized for each project and include instructions and boiler plate text to make them useful to project teams. CDC UP Process Guides help project teams comply with federal regulations, Public Health Information Network (PHIN) standards and CDC policies by presenting requirements in a consistent, easy to understand format.

This presentation will provide an overview of the development of the CDC UP Process and highlight the resources available to project managers. In addition, the presentation will include application of the CDC UP for developing and managing EHDI tracking and surveillance systems. These resources can be accessed at <http://www.cdc.gov/cdcup/>.

Keywords: Project Management

Title: As Easy as Stone Soup: Developing a Statewide Hearing Aid Loaner Bank

Author(s): Kirsten R. Coverstone, Audiologist

Affiliation(s): University of Minnesota, Lions Infant Hearing Screening Program

Presented by: Kirsten Coverstone

Abstract: The Lions Infant Hearing Screening Program Loaner Bank of Minnesota was established in 2000. After 6 years of success supporting Minnesota families the program has insight to offer re: (1) Changing challenges into achievements with in a state wide loaner hearing aid bank; (2) Locating various funding sources to assist with inventory, staffing, & revolving costs; (3) Identifying important points of interest for the parental and audiologist feedback survey

Over the six years approximately 200 families have benefited from the support of the loaner bank. The remarkable progress despite the lack of on-going state funding is due to the support of local service groups, manufacturers, families and audiologists. In Minnesota hearing aid funding has improved but is limited and without a loaner bank timely intervention would not have happened for many of Minnesota's children. This presentation will look at the role of community organizations in establishing and maintaining a statewide loaner hearing aid bank for newly identified infants and young children.

Keywords: Loaner Bank, Hearing Aids, Survey

Title: HEAR for Kids Loaner Hearing Aid Bank

Author(s): Lylis E Olsen, MS, MPH, Audiologist

Affiliation(s): The EAR Foundation of Arizona

Presented by: Lylis Olsen

Abstract: The EAR Foundation of Arizona's HEAR for Kids program is in its seventh year of operation. The program was developed in response to community identified needs. Program guidelines were established by pediatric audiologists and other community members. Loaner hearing aids are available to all Arizona families with children who are newly identified with hearing loss. Approximately 200 new technology aids are available through an online request system. The loaner hearing aids are available while the family works toward qualifying for public services, obtains the necessary referrals and authorizations for insurance coverage or are awaiting cochlear implantation. Most loans are between 4 months a one year in duration. Program funding, set-up, costs, application and fitting forms and outcomes will be shared.

(1)The learner will: Understand the costs involved in setting up and maintaining the loaner program; (2) Know how to access copies of the fitting and request forms online; (3) Be able to identify potential funding sources in their own community

Keywords: Hearing Aid, Loaner Bank, Pediatric Audiology

Title: Transitioning to Public School from Early Intervention Services

Author(s): Angela Yarnell Bonino, Jackson Roush

Affiliation(s): Division of Speech and Hearing Sciences, University of North Carolina
School of Medicine, Chapel Hill, North Carolina

Presented by: Angela Yarnell Bonino

Abstract: In many areas throughout the United States, school districts rely on audiological evaluations and recommendations from students' private audiologists, due to the limited availability of school-based audiologists. Typically, private audiologists are unable to attend the Individualized Family Service Plan (IFSP) and Individual Education Program (IEP) meetings for students. As a result, speech-language pathologists, special education teachers, early intervention coordinators, or families may be placed in the position of interpreting the audiological findings and recommendations. In many cases, this individual has limited exposure to students with hearing loss and/or difficulty interpreting audiological evaluations and recommendations. This session will focus on information that is relevant for personnel who work with families as they move from early intervention services to the public school district to ensure a smooth transition, consistent with federal regulation for special education (IDEA 2004) and 504 services. Specific guidelines will be presented on how to ensure that assessments and recommendations are educationally relevant to assist the IEP team in determining the appropriate educational placements, modifications and assistive technology.

Keywords: transition, preschool, assessment, accommodations

Title: Parents & Professionals UNPLUGGED

Author(s): LEEANNE SEAVER, M.A., Executive Director, JANET DESGEORGES, Outreach Director

Affiliation(s): Hands & Voices National

Presented by: Dinah Beams, JoDee Crace, Marcy Dicker, Susan Dickinson, Janet DesGeorges, Cheri Dowling, Cami Geilenfeldt, Julia Hecht, Lisa Kovacs, Molly Martzke, Stephanie Olson, Linda Rose Pippins, LEEANNE SEAVER, Kylie Sharp, Rachel St. John, Elisa Wells

Abstract: What do parents and professionals say about the early intervention systems that serve their families and children—off the record and “unplugged”? This lively panel discussion covers a spontaneous agenda of family support topics from “the best advice I ever got from my parent-infant facilitator” to “what I would never admit to my audiologist” to “holding my tongue during the home visit” to “a prescription for a doctor” and much more.

Using the principles of “Open Space” meeting design, (see www.openspaceworld.org or www.co-intelligence.org/P-Openspace), this “Unplugged” session will operate on the premise that 1) if the topic comes up, it’s worth talking about, and 2) the issues that are MOST important to the participants will be raised. Facilitation of discussion is subtle and non-directive.

The goal of the session is to create a safe place to share issues, concerns and feelings in a positive, productive manner. Expected outcomes are for the EHDI audience to gain sensitivity to the parent perspective, for parents to gain a better understanding of the professional experience, and to encourage authentic end-user feedback from both parent and professional points of view that can promote the improvement of EHDI service delivery models.

Keywords: Family Support, Early Intervention, Medical Home, Parents