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

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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

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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

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**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 lead 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

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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

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Presented by: Jill Ellis

Abstract: Adapting and Expanding Knowledge and Skills of Early Intervention Providers 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

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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

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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

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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

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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


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

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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