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

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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

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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

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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

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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 an 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

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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

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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

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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

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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

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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

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**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:**

1. Define the audiological diagnostic "indicators" of Auditory Neuropathy.
2. Identify audiological protocols currently used in the diagnosis of Auditory Neuropathy.
3. Identify factors that may contribute to parent and interventionists frustration concerning educational planning for children with Auditory Neuropathy.

**Keywords:** Auditory Neuropathy, Early Intervention