

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

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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

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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

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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.

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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

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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

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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

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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