X. Program Narrative - Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening – Mississippi
Grant Announcement # HRSA 08-030/CFDA No. 93.251

INTRODUCTION

Mississippi's Early Hearing Detection and Intervention (EHDI-M) program has been in existence since 1997, collaborating statewide with hospitals and service providers to ensure infants with potential hearing loss are evaluated, identified, and referred for necessary early intervention services by six months of age. The Mississippi State Department of Health's (MSDH) Office of Child and Adolescent Health (OCAH) is responsible for the implementation of Maternal and Child Health programs and services such as the Children with Special Health Care Needs (CSHCN) program, Genetics and Newborn Screening Program, Birth Defects Registry, and the First Steps Early Intervention System (FSEIS).

EHDI-M has been established as an integral part of the MSDH FSEIS, which is responsible for the implementation of Part C of IDEA. Since EHDI-M functions as part of FSEIS, EHDI-M activities and personnel are integrated in the Part C system. Each child identified by EHDI-M with a confirmed hearing loss is offered a full array of early intervention services as required by Part C and state law. For this reason, EHDI-M is in an ideal position to enlist collaboration for tracking, follow-up, and monitoring goals.

Family-to-family support is made available in Mississippi through the work of Hearing Resource Consultants (HRC's). HRC's work in particular geographic regions. When a baby refers, the HRC contacts the family to share information about the diagnostic process. At the family's request, the HRC might accompany the family to the diagnostic appointment and further explain the results. HRC's are included as part of the Early Intervention evaluation team. The HRC explains intervention options, giving unbiased information to the family members. The Individual Family Service Plan is written considering the families' priorities, resources, and concerns.

Support systems exist for families with children who have been identified with hearing loss. If family members give written consent, the HRC shares their information with another family in the support network. In more populated areas of the state, family support groups have been formed and facilitated by the Hearing Resource Consultants. Parent advisors within the FSEIS in specific health districts are also instrumental in establishing these support systems.

As EHDI-M works to reduce lost to follow-up numbers and to ensure children with hearing loss are identified and treated, it is critical to adopt new procedures to integrate and coordinate services with families, specialists, physicians, and the Medical Home. As reported in the 2003 National Survey of Children's Health, 33.8% of Mississippi's children birth to 17 years of age received care from a physician who meets the American Academy of Pediatrics' (AAP) definition of Medical Home (See Attachment 7).

EHDI-M has identified 3 measurable objectives to reach the goal of 100% of children with hearing loss having a Medical Home by 2016:

1) EHDI staff will educate families on the importance of a Medical Home to coordinate:
   a) referrals to specialists,
   b) diagnostic information,
   c) interventions;
2) Families will locate a pediatrician/physician in the community or region who represents the Medical Home;
3) Additional fields will be added to the EHDI data base to include information about the Medical Home, Primary Care Physician, and other medical specialists utilized by the family.

NEEDS ASSESSMENT

In 2006, Mississippi reported 44,863 live births. 44,737 babies were born in 48 hospitals; 126 were non-hospital deliveries. Of those live births, 43,942 (98%) were screened for possible hearing loss. There are 144 Certified Audiologists in Mississippi. Of these, 41 have skill and expertise in providing diagnostic evaluations for newborns and young children. Five hundred and forty babies (1.23%) were referred for further audiological evaluation. On average, Mississippi identifies .1% of babies with bilateral hearing loss. The total number of babies with confirmed hearing loss (both bilateral and unilateral) born in 2006 was 64 (.14%).

Mississippi's lost to follow-up numbers have decreased. In 2006, 81 babies were lost to follow-up between the hospital and outpatient screenings; 26 were lost between outpatient screening and diagnostic evaluation; and none were lost to follow-up between diagnosis and entry into our Early Intervention System.

Year	2003	2004	2005	2006
Refer Rate	1.14	1.04	1.06	1.05
# Referred	408	426	427	540
Average age of diagnosis in months	2.22	2.51	1.88	2.22
# Completed diagnostic	341	343	346	420
% Completed diagnostic	83%	80.8%	81%	78%
# Completed diagnostic < 3 months	258	262	291	337
% Completed < 3 months	61.5%	61.5%	68.2%	63%
Confirmed Loss	66	70	65	70
% Referred EI < 6 months	84.3%	77.2%	89.2%	91.4%
# Lost to Follow	55	64	64	21

Of the 540 babies referred from newborn hearing screening, 155 children had Primary Care Providers (PCPs) documented in the EHDI-M database. Many of the identified providers are likely the neonatologist from the birthing hospital and are subject to change

almost immediately following discharge from the hospital. A number of variables contribute to the large number of children discharged without an identified PCP: failure of hospital staff to ascertain a community PCP or Medical Home; information regarding the PCP or Medical Home not being included in information forwarded to the EHDI-M data manager; and/or families not identifying a PCP or Medical Home.

METHODOLOGY

The nurse/technician who performs the initial hearing screen completes the family demographic information and Medical Home sections on the Newborn/Infant Hearing Screening Report (Attachment 7). EHDI-M obtains additional child/family information through the Health Department's Patient Information Management System (PIMS), genetics database, and the FSEIS Data System. Increased identification of and communication with Primary Care Providers and Medical Home is being proposed to decrease lost to follow up numbers. Several procedural changes are being implemented to improve outcomes for families.

Nurses/technicians disseminate brochures regarding newborn hearing screening to families at the time of screening. If the child passes the screening, no further testing is recommended, unless the child is considered to be "at-risk." If the child refers from the screening, a third outpatient screen or a diagnostic appointment is scheduled by the nurse/technician. The nurse relays the appointment information (date, time, location) to the family and explains the importance of follow-up. As part of technical assistance visits performed by the Hearing Screening Coordinator, nurses are reminded to fill out the Medical Home section on the Newborn/Infant Hearing Screening Report (Attachment 7), which is a component of EHDI-M Policy and Procedure.

If a child fails to show for an outpatient screen at the hospital or a diagnostic evaluation, the Medical Home will receive a fax from the Hearing Screening Coordinator requesting verification that the child is an established patient. The Medical Home will fax back the Fax-Back form (in Attachment 7) to EHDI-M within 48 hours. The form will indicate whether the child is a patient and when the child's next pediatric appointment is scheduled. The Hearing Diagnostic/Intervention Coordinator will notify the Medical Home: (1) the child missed their follow-up screening or diagnostic evaluation and (2) another appointment has been made for their patient.

The Hearing Resource Consultant (HRC) contacts the family to remind them of their child's Audiologic Diagnostic appointment(s). The HRC helps the family address barriers that may hinder their ability to keep the scheduled appointment(s). The HRC explains the importance of follow-up, what to expect at the appointment, and important pre-testing instructions.

A new procedure requires the HRC to verify the child's Primary Care Provider with the family and explain the importance of having a Medical Home that houses information about all of the child's wellness and special medical needs. The HRC will document information regarding the Medical Home, PCP, and other medical specialists on the HRC

Checklist, which they will forward to the Hearing Diagnostic/Intervention Coordinator at the state EHDI office. The Diagnostic Coordinator will enter this information into the EHDI data base, and as appropriate, in the EI data base.

If the infant is evaluated by the Audiologist and diagnostic testing cannot be completed, the Audiologist reschedules the patient for further testing. The Audiologist sends the Audiological Diagnostic/Follow-up Report (Attachment 7) to the EHDI-M state office. The Diagnostic/Intervention Coordinator will notify the child's Medical Home and HRC about the inconclusive results and additional appointment, facilitating follow-up with the family by both parties.

Following diagnostic evaluation, the Audiologist sends the Audiological Diagnostic/Follow-up Report (Attachment 7) to the EHDI Hearing Diagnostic/Intervention Coordinator along with all test results and reports. The Hearing Diagnostic/Intervention Coordinator logs the information into EHDI-M's database. A Release of Information will be obtained by the HRC or the child's Service Coordinator to share diagnostic information with the Medical Home. The Audiological Diagnostic/Follow-up Report (Attachment 7) will be faxed to the Medical Home, as well as to the child's HRC. If a hearing loss is confirmed, the HRC will visit the Medical Home to discuss hearing loss, the effects on development, and possible interventions.

Once the child is enrolled in the early intervention program, the Service Coordinator will provide the Medical Home with Early Intervention evaluation(s) and the Individual Family Service Plan (IFSP). Any prescriptions needed to carry out the IFSP will be requested from the Medical Home by the Service Coordinator. The Service Coordinator will facilitate relationships between EHDI-M, FSEIS, the family, Medical Home, and other medical specialists.

WORK PLAN

Quarterly meetings of the EHDI-M Advisory Board are held at the University of Mississippi Medical Center in Jackson. The Advisory Board includes a Chapter Champion, Pediatric Otolaryngologists, Pediatricians, Speech Language Pathologists, Audiologists, EHDI-M's Director and EHDI's Audiology Consultant. The purpose of these meetings is to discuss how many children are screened, referred from newborn hearing screening, have confirmed hearing loss and the type of hearing loss, and number of children pending diagnosis. At the first Advisory Board Meeting of 2008, the number of children lost to follow-up will be reported, as well as the number of children who have an identified Medical Home.

The Hearing Screening Coordinator will provide technical assistance to the 48 birthing hospitals in the state regarding the newly adopted EHDI-M Policy and Procedures to ensure the Medical Home information is included on the Newborn/Infant Hearing Screening Report (Attachment 7). The timeline to start this process is April 1, 2008.

The HRC will educate families on the importance of a Medical Home to coordinate

referrals to specialists, to maintain diagnostic information in a central location, and to develop and implement interventions. HRC's and Service Coordinators will assist families in locating a pediatrician/physician in the community or region who represents the Medical Home. The HRC will forward information about the family's Medical Home and other providers to the Hearing Diagnostic/Intervention Coordinator. The timeline to start this process is April 1, 2008.

The Hearing Diagnostic/Intervention Coordinator will log information on the child's Medical Home and other medical providers into EHDI-M's database. This information will allow EHDI-M to have a central registry of Medical Homes and providers working with children and their families with confirmed hearing loss. The timeline to start this process is April 1, 2008.

EHDI-M's Audiology Consultant will make regular technical assistance visits to identified Pediatric Audiologists to discuss the importance of sending diagnostic reports and no-show information to the EHDI-M office and to Medical Homes. The timeline to start this process is April 1, 2008.

The FSEIS Business Systems Analyst, who assists EHDI-M in the management of the registry and data, will add additional fields to the data system to capture information about Medical Home and other providers. The timeline to start this process is April 1, 2008.

EHDI-M will work with MSDH Office of Health Disparities to include providers in training on culturally sensitive issues. EHDI-M and FSEIS have parent education brochures printed in Spanish and Vietnamese. Through MSDH families have access to interpreters as needed.

RESOLUTION OF CHALLENGES

The Medical Home in a child's life may change depending on their medical needs. For a variety of reasons, the Medical Home for a newborn released from the hospital might be the Neonatologist. If a child had an extended stay in the Neonatal Intensive Care Unit, other specialists who continue to address acute, chronic, and/or long-term needs become the Medical Home. Many first-time parents have not identified a pediatrician in the community, or use a general practitioner for all of their family's medical needs. In areas where there is a lack of Medicaid providers for primary care as well as special services, families utilize the emergency room for acute care and after hours care. Wellness care, if sought at all, may be the local health department clinic. These factors contribute to a small number of children having a Medical Home.

Mississippi is a poor, rural state with limited access to medical providers and pediatric audiology services. Other barriers include lack of transportation, varying levels of family motivation and education, and limited public and private insurance reimbursement for services. Availability of community-based or regional services may be a contributing factor in lost to follow-up statistics. Audiologists are constantly being sought to provide

community and regional services to children, reducing the need to travel to Jackson for services.

Several HRC's are Audiologists certified and licensed by the state of Mississippi. These professionals are utilized to make ear mold impressions for children whose families are unable to make a trip to an audiologist's office. The impressions are mailed by the HRC to the nearest audiology facility. The audiologist orders the ear molds then mails them back to the HRC for dispensing or mails them directly to the family. This added service to families helps families with timely audiologic management in the home.

EHDI-M's Audiology Consultant makes regular visits to Pediatric Audiologists to emphasize the importance of reporting to EHDI-M and to Medical Homes. Audiologists must send reports in a timely fashion to EHDI-M so families can be informed and empowered in designing appropriate interventions for children with hearing loss. Mississippi's EHDI, EI, and medical systems work together to build a system where children do not fall through the cracks.

HRC's are instrumental in educating families on hearing loss, intervention options, the importance of Audiological and Medical Home follow-up, and services provided through First Steps Early Intervention for children with diagnosed hearing loss. The HRC's frequent contacts with families and the Medical Home contribute to reduction in lost to follow-up statistics. This level of coordination is needed if the 1-3-6 goals of EHDI are to be achieved.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

HRC's call families to remind them of Audiological appointments. They obtain a Release of Information, either directly or through a FSEIP Service Coordinator, to share information about children with a confirmed hearing loss with the family support network. A Release of Information allows the HRC to share information with the Medical Home. The HRC's work with Early Intervention Service Coordinators to link families to services, including early intervention providers, and assist the Individual Family Service Provider (IFSP) team in developing outcomes and interventions. The HRC's serve as coaches and mentors for early intervention providers working with families of children with hearing loss. HRC's are included in transition planning for children approaching their third birthday, to identify appropriate preschool and Part B services. The HRC's are critical to continuity of care for Mississippi's children with hearing loss.

EHDI-M's Audiology Consultant makes regular visits to identified Pediatric Audiologist on the importance of reporting necessary paperwork to the EHDI-M. This individual will ensure the Audiologists work closely with EHDI-M to include Medical Homes in the process of identifying children with hearing loss.

The Hearing Screening Coordinator provides technical assistance visits to the 48 birthing hospital in the state on EHDI-M Policy and Procedures. The Hearing Screening Coordinator has established strong relationships with the birthing hospitals in

Mississippi. The Hearing Screening Coordinator monitors all Newborn/Infant Hearing Screening Reports (Attachment 7) received by EHDI-M and details all hearing screening logs submitted by hospitals. With continued funding from HRSA, the Hearing Screening Coordinator will monitor whether Medical Homes are documented on the Newborn/Infant Hearing Screening Report and entered into the EHDI data base.

The Hearing Diagnostic/Intervention Coordinator will add information about the child's Medical Home into EHDI-M's database. The Business Systems Analyst will build reports to identify null fields in the EHDI data base, to calculate numbers of children with an identified Medical Home, and to identify children who failed to show up for follow-up appointments.

ORGANIZATIONAL INFORMATION

The mission of MSDH is to promote and protect the health of the citizens of Mississippi. The MSDH vision is to strive for excellence in government, cultural competence in carrying out its mission, and local solutions to local problems. MSDH identifies its values as applied scientific knowledge, teamwork, and customer service. To guide development of program objectives and strategies, MSDH places emphasis on strategic and operational planning, community assessment, information systems, data analysis and quality review. Interventions are based on causes of morbidity.

MSDH takes a team approach to fulfilling its mission, with customers as the focus. MSDH prepares staff and the public through program and system performance monitoring, increased surveillance, and an enhanced system of early detection, reporting, and response. The MSDH Health Services Division is responsible for the implementation of Maternal and Child Health programs. The Offices of Child and Adolescent Health include the Children with Special Health Care Needs program(Title V), Genetics and Newborn Screening Program, Birth Defects Registry, and the First Steps Early Intervention System. Both FSEIS and Title V funds are used to support the EHDI program, in addition to the grant from HRSA and state general funds.

In 1997 Mississippi was one of the first states to pass hearing legislation. Legislation mandates that all hospitals which birth 100+ babies a year conduct universal newborn hearing screening. Approximately 44,000 babies are born each year in Mississippi. In 2006, 98% of all live births were screened. The majority were screened in one month or less. Mississippi identifies approximately .1% of children with a bilateral hearing loss, and another .05% with a unilateral hearing loss. These numbers are consistent with national averages. Currently a task force is working on proposing hearing aid legislation to the Mississippi Legislature in the 2008 legislative session.

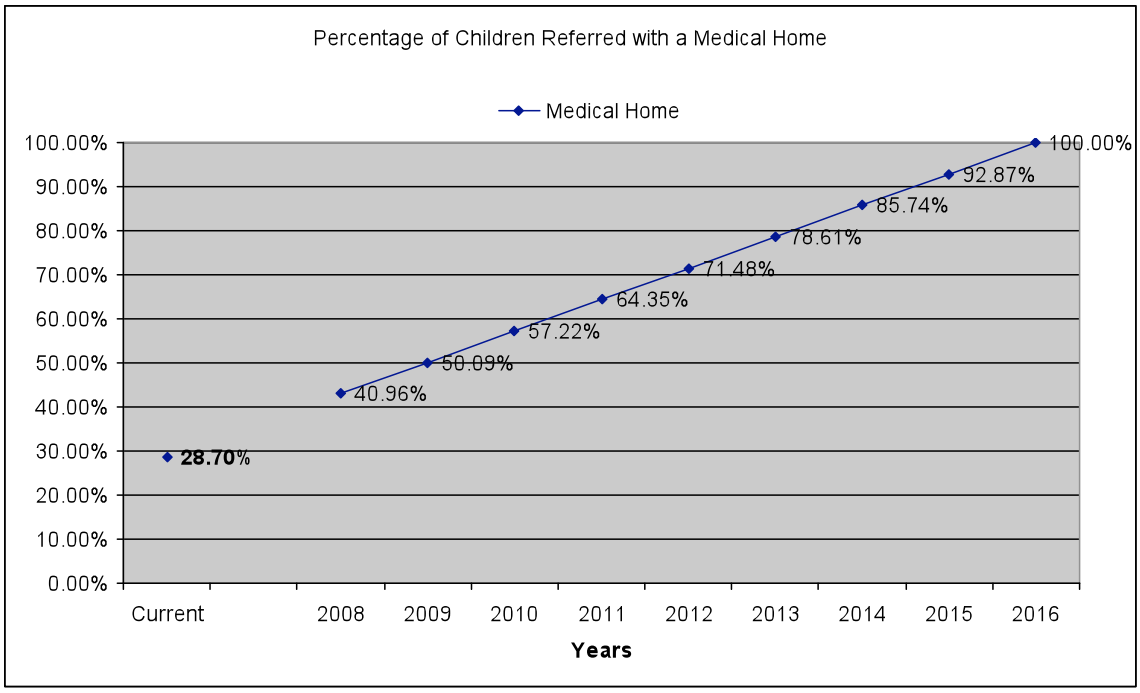
The EHDI director supervises contractual staff known as HRC's. The HRC's work with the FSEIS Service Coordinator staff at the local level to plan appropriate evaluations/assessments, to present unbiased information about intervention options to families, to develop an Individual Family Service Plan, to identify providers who can help families obtain the identified outcomes, and to help plan for transition to other

preschool or educational programs.

The state is currently reviewing proposals for an integrated patient information data system. The Early Intervention and Early Hearing Detection and Intervention data systems are currently housed in the FSEIS/EHDI office. Information from the EHDI data system is crossed-over to the EI system as appropriate (multiple developmental issues and/or confirmed hearing loss). Within the EHDI-M office is a Screening Coordinator, who coordinates screening activities with the hospital nurseries and manages the EHDI screening data. The EHDI Diagnostic/Intervention Coordinator coordinates the diagnostic paperwork with audiologists and the Hearing Resource Consultants and enters diagnostic data into the EHDI data system. Hospitals and audiologists are required by legislation to provide screening and diagnostic information to the EHDI program.

The EHDI Advisor Board, made up of professionals from across the state, meets three times a year to review research and data and to make program recommendations. Members include pediatricians, otolaryngologists, speech/language pathologists, audiologists, parents, hearing resource consultants, an audiologist consultant and the EHDI Director.

ATTACHMENT 7



ATTACHMENT 4

Biographical Sketches of Key Personnel: Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening – Mississippi
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Melanie Randle began working as a Hearing Resource Consultant (HRC) with the Mississippi Department of Health's Early Hearing Detection and Intervention Program in April 2007. She earned a Master of Science in Audiology from Vanderbilt University in 2000. Upon graduation, Ms. Randle completed her clinical fellowship in audiology at the VA Medical Center in Houston, Texas. She moved to Oxford, Mississippi and assumed a position as a diagnostic audiologist at the North Mississippi Regional Center in November 2002. In November 2003, Ms. Randle began working as a clinical audiologist at the University of Mississippi Speech and Hearing Center. She continues to work one day per week as a clinical audiologist at the Speech and Hearing Center in addition to her work as a Hearing Resource Consultant.

Sheryl V. Malone has four years of consulting experience with Early Hearing Detection in Mississippi. She graduated from Mississippi College with a B.S. in Deaf Education K-12. She certified in Education of the Learning Disabled K-12 from Jackson State University. Sheryl participated in the World Class Teacher Program at Mississippi State University and achieved National Board for Professional Teaching Standards Certification. Sheryl has instructed deaf/hard of hearing students and learning disabled students for twenty-four years. She

Misty Johnson began working for Early Hearing Detection and Intervention (EHDI-M) program as an Audiology Consultant/Hearing Resource Coordinator in 2006 to present. She is a graduate from the University of Southern Mississippi with Bachelor of Science (B.S). in Speech Pathology/Audiology in 1996. Misty has experience in performing diagnostic evaluations on children and adults (including ABRs, both sedated and non-sedated). Misty works on contract as a clinical audiologist at the University of Mississippi's Speech and Hearing Clinic. At this clinic, she supervises students who are pursuing a Master's Degree in Speech Pathology.

Kimberley R. Gibson received Bachelor's and Master's Degrees in Speech-Language Pathology from the University of Southern Mississippi. She has 12 years of professional experience which have included working in the public school system, hospitals, outpatient rehab, nursing homes and private practice spanning all ages and stages of life. Her areas of interest are in pediatrics providing evaluation and treatment of disorders of articulation, language, swallowing and feeding, oro-myofunction, auditory processing, and auditory/oral rehabilitation of the hearing impaired.

Rita Hall, M.S.CCC/SLP is a Speech Language Pathologist who graduated from Murray State University with a Bachelor of Science degree in Communication Disorders and the University of Louisville with a Master of Science in Speech Pathology. She has over 21 years of experience working with children birth to five. She has worked with a variety of

disabilities including the hearing impaired infant s, children and adolescents in a variety of settings ranging from homes, clinics, schools and hospitals. Rita is currently providing speech/language services to birth to adolescents through private practice. She has been a Hearing Resource Consultant for the Southern Coastal counties of Mississippi since February, 2007.

Christi Magee graduated from University of Southern Mississippi in 1996 with a Bachelor of Arts degree in Speech and Hearing Sciences and in 1998 with a Master of Science degree in Audiology. She is a member of Gamma Beta Phi, SSHA Professional Affiliations: American Speech & Hearing Association, Mississippi Speech & Hearing Association, Mississippi Early Childhood Association. Christi holds professional licenses with ASHA Certificate of Clinical Competence – Audiology, Mississippi Department of Health – Audiology, Mississippi Department of Education – Elementary Education, Special Education, Audiology, Language/Speech Clinician, Biology, Social Studies, and General Science. She has served as an Educational Audiologist for 6 years, Special Education Teacher for 2 years, Language/Speech Clinician for1.5 years.