X. Program Narrative

PURPOSE OF THE PROJECT

This application is submitted by the Wisconsin Department of Health and Family Services (DHFS), Division of Public Health (DPH) in response to the CFDA # 93.110 – *Priority One: Implementing and Sustaining Universal Newborn Hearing Screening and Intervention Programs.*

The early identification of infants with hearing loss is an important public health objective. The Joint Committee on Infant Hearing (JCIH), 2000 Statement recommends that: 1) all infants be screened by no later than 1 month of age; 2) infants with hearing loss be diagnosed before three months of age; and 3) infants with hearing loss receive intervention by no later than six months of age.

Permanent congenital hearing loss is one of the most frequently occurring birth defects. Approximately two to three infants per thousand (200-300) are born with some level of hearing loss annually in Wisconsin. 1999 legislation was passed that states "get text from grant"

With the assistance of the Wisconsin Sound Beginnings (WSB) Program, all but two hospitals have voluntarily implemented universal newborn hearing screening (UNHS) programs, thereby avoiding a state mandate.

Although much progress has been made toward the goal to screen all newborns, national data indicate that nearly half of all newborns who refer on the hearing screen do not return for follow up services. Research indicates that infants enrolled in an intervention program by six months of age perform better on school-related measures than children who did not receive intervention. It is critical that early hearing detection and intervention (EHDI) systems be in place to assure that infants receive timely diagnostic and intervention services.

The WSB Program was created with the first cycle of federal Maternal and Child Health Bureau (MCHB) grant funds. The purpose of WSB and this project is to meet the goals listed below in order to assure a sustainable family-centered and culturally competent EHDI system for Wisconsin's children and their families *(Appendix A1)*.

Goal 1: Screen all babies for hearing loss prior to discharge from the hospital. **Goal 2:** Assure that all babies who do not pass the hospital screening receive thorough diagnostic services by three months of age. **Goal 3:** Assure that all children identified as deaf or hard of hearing receive comprehensive early intervention services and smooth transition into appropriate early childhood education services. **Goal 4:** Assure family's awareness of family support organizations. **Goal 5:** Assure that every child that does not pass the hospital screening has an informed medical home. **Goal 6:** Establish a comprehensive follow-up and tracking system statewide.

NEED ASSESSMENT

The number of Wisconsin hospitals with universal newborn hearing screening (UNHS) programs has increased from two hospitals (2%) in 1997 to 100 of 102 (98%) birthing hospitals in 2004. In 2003 there were 68,510 live births in Wisconsin, which occurred primarily in 102 birthing facilities but also included 915 home births. Of these births, nearly 95% of newborns were screened.

Screening rates were tracked initially through a self-report survey to hospitals. However, as of April 2002 hearing screening results were added to the Metabolic Blood Screening Card. This was the first crucial step in allowing WSB to evaluate screening and referral rates, and provided the foundation for building a data and tracking system. Among the 69,638 babies with blood cards from 9/1/2003 – 8/31/2004, 65,351 (94%) were screened, 1,166 (1.8%) referred, and

only 73 (0.1%) refused screening. Less than 3% of blood cards do not contain hearing screening information. Hospital personnel complete hearing screening information on the blood card, and the Wisconsin State Laboratory of Hygiene (SLH) staff do initial follow-up to obtain missing hearing screening information *(Appendix B-a)*. Initially 15% of cards had missing fields but a series of SLH/WSB newsletters and follow-up by SLH staff have resulted in a reduction to 3%. This is consistent with the percent of blood screening cards missing information before adding the newborn hearing screening fields.

In September 2001 DPH received a four-year Centers for Disease Control and Prevention (CDC) grant to develop a web-based EHDI data and tracking system. This grant has allowed WSB to develop the Wisconsin Early Hearing Detection and Intervention Tracking Referral And Coordination (WE-TRAC) System. The WE-TRAC system is a part of the Wisconsin Public Health Information Network (PHIN), developed by the DPH and the Division of Information Technology (DoIT) at the University of Wisconsin. Hearing screening data is transmitted nightly via secure messaging from the SLH to DoIT, where it is automatically loaded into WE-TRAC. WE-TRAC business logic then determines the appropriate action for each record, sending only babies that need further screening to individual hospital queues, where users can view lists of babies associated with their organization. This system alerts well baby birthing units, special care nurseries, and audiologists that babies need follow-up, allows these providers to make electronic referrals and enter re-screening, medical home and diagnostic results into the WE-TRAC system.

WE-TRAC was piloted with ten birthing units representing approximately one fifth of Wisconsin births for about one year and saw a lost to follow-up rate of less than 10%. WSB with the Wisconsin Speech Language Pathology and Audiology Association (WSHA) developed the

Confirmation of Hearing Loss and Referral (CHL) form that is available as a fillable Word document or as a printable WE-TRAC form that can be used for medical records documentation, or shared with consent *(Appendix A2)*. Testing of the CHL form by audiologists was included in the WE-TRAC pilot. From analysis of the 31 CHL forms submitted, the average age of identification is 3.65 months.

The pilot ended in May 2004, and the enhanced system is entering the testing stages. A phased roll-out of the new version of WE-TRAC is expected in 2005, which will allow data collection and trend analysis of individual and aggregate screening, re-screening, and diagnostic audiology results. The next version, anticipated for March of 2006, will allow the collection of early intervention services, medical home information, as well as the ability to track and follow-up on babies that were not entered into WE-TRAC through the Metabolic screening card. An increase in the percent lost to follow-up is anticipated when the WE-TRAC system expands to include records where the birth hospital is not known, as well as to include a greater number of rural hospitals, home births, and special populations. Lost to follow-up will be monitored via WE-TRAC.

Along with the development of a web-based data collection and tracking system, WSB has made significant gains in creating a comprehensive system of early hearing detection and follow-up services. A multi-disciplinary EHDI Implementation Work Group was established in 2000 to act as an advisory committee *(Appendix A3)*. This group, which meets quarterly, is comprised of parents, deaf adult, pediatricians and family practice physicians, audiologists, Birth-3 providers, and many other disciplines. The EHDI Implementation Work Group developed a comprehensive program model *(Appendix A-a)* which exemplifies a continuum of care that has helped guide WSB system development. Initial focus was primarily directed

towards developing and supporting screening, diagnosis including genetic services, and intervention.

Enhancing the skills of professionals statewide that provide services to infants referred from UNHS programs has been an important piece of WSB. Some initiatives such as a three-part pediatric audiology training, intensive trainings for early intervention consultants, and outreach efforts to medical home providers have proven very effective. Audiologists continue to have access to pediatric continuing education through WSBs collaboration with WSHA and now have clear standards and pediatric protocols to follow. The WSB Program also created new and sustainable systems of education and support through publications such as the EHDI Newsletter series, and the Babies and Hearing Loss publication series for families and professionals. Regular updates are provided to pediatricians in the Wisconsin Chapter – American Academy of Pediatrics' (WIAAP) newsletter, the "Wisper". WE-TRACs online documents include a "just in time" letter for the primary care provider (PCP) that outlines the important role of the medical home, next steps for evaluation and sources for additional information. The letter is co-signed by the WIAAP and Wisconsin Academy of Family Physicians (WAFP) Champions and CSHCN Medical Director. WSB and WIAAP have revised the AAPs checklist for medical home providers to make Wisconsin specific. This gives providers an efficient means to see and record necessary follow-up activities.

In January 2002, the WSB program convened an invitational Parent Network Summit, where families identified statewide family support needs such as the importance of access to unbiased information at the time of diagnosis. WSB with its family partners and Birth-3 compiled unbiased information into the "Babies and Hearing Loss Notebook for Families" that is now available to families by all Wisconsin pediatric audiologists and is also available on the web

with the plan to make available in Spanish. Another need identified at the Summit was a Wisconsin Families of Deaf and Hard of Hearing list serve which was quickly established by one of the attending parents. In response to a third identified need, the first annual conference for parents was held and hosted 35 families. The conference attendance doubled the following year and is anticipated to double again to150 families in 2005 *(Appendix F-a)*.

The most fervent recommendation to come out of the Parent Summit was the need for direct and immediate parent-to-parent support after the child's identification. From that recommendation the Guide-By-Your-Side (GBYS) Program was initiated *(Appendix F2)*. The GBYS Program is supported through a grant from the Department of Public Instruction (DPI), IDEA preschool discretionary grant funds and is administered through the Wisconsin Educational Services Program for the Deaf and Hard of Hearing (WESPDHH). GBYS provides an opportunity for a family who has just learned of their child's hearing loss to meet with another trained parent of a deaf or hard of hearing child called a Parent Guide. The program provides families of children 0-6 years of age, up to three home visits. Parent Guides may opt to continue to support the family informally beyond the third visit. At least one home visit must be made in conjunction with the Birth-3 Program for children under three years of age.

Parent Guides are organized into Regional Parent Guides (English speaking parents who serve the regions in which they live) *(Appendix B-b)* and Statewide Parent Guides (Parents with special experiences who serve families through out the state). Some Statewide Parent Guides are bilingual *(Appendix B-c)*. Currently, there are Parent Guides whose first languages are Spanish and two Deaf Parent Guides whose first language is American Sign Language. A mother of a young child with Usher's Syndrome is a Statewide Parent Guide who meets with families across the state with children who are deaf, blind, or multiply impaired.

The GBYS program is free, voluntary, and confidential. Currently, referrals are made with parent consent mostly through the child's audiologist via the CHL form. The GBYS Program is coordinated by the WESPDHH Birth to Six Services Coordinator *(Appendix B-d)*. WSB is looking to include referrals to this program through the WE-TRAC system in future development. The family, early intervention program or PCP may also make referrals.

Clear eligibility and best practice statements have been instituted in the Birth-3 Program related to young children who are deaf or hard of hearing. County Birth-3 Programs have access to a regional network of Birth-3 Consultants to call upon if they need assistance providing services to a deaf or hard of hearing child. They may also access WESPDHH for evaluation and consultation services.

Programs that support families of newly identified children such as the Annual Conference for Families of Deaf and Hard of Hearing Children, WI Hands & Voices and the GBYS Program have been implemented and offer support statewide. Many other local support programs have begun as a result of the WSB Program's support and guidance.

The WSB has successfully integrated key program components into the DPH sustained infrastructure. The WSB Program Director's position was initially a contracted project position. This position became a permanent state position with plans to support it with Title V dollars beginning in Year 2 of this grant. Newborn hearing data collection has also become a sustainable entity due to close collaboration with the SLH. As of December 2003, the SLH hired a full-time, data entry/follow-up person to enter the results of the hearing screening into their database and to gather missing information from hospitals. The SLH also directed a part of another position to supervise the hearing screening data entry position. This is a demonstrated collaborative effort with SLH without funding from WSB.

WE-TRAC development, from its inception, looked to integrate with other DPH data initiatives. WE-TRAC was the first EHDI tracking system developed to be National Electronic Disease Surveillance System (NEDSS) compatible and utilize secure Health Alert Network (HAN) messaging. The HAN and NEDSS have provided components of the infrastructure needed for WE-TRAC and have reduced the cost to WSB for its development and future maintenance.

The WSB has built strong communities of practice around early hearing detection and intervention. This has allowed for the continuation of costly program components such as the Babies and Hearing Loss Notebook for Families, the Annual Parent Conference, and the GBYS Program which are now being organized and funded through the WESPDHH with active support and participation from the WSB Program. For more information about WESPDHH and GBYS go to www.wesp-dhh.wi.gov.

DATA REQUIREMENTS

The WSB Program will collect and analyze data in order to monitor and provide technical assistance for program improvement. The WSB Program will report annually to the MCHB the requested data items: number of live births in Wisconsin, the number of infants screened prior to hospital discharge (WE-TRAC and SLH data), and the number of infants suspected of a hearing loss with a confirmed diagnosis by three months of age (WE-TRAC data). Initially WSB will depend on the information collected manually through the GBYS program's Services Summary form *(Appendix A4)* and provided by the State Birth-3 Program to report annually on the number of infants diagnosed with a hearing loss enrolled in the State's early intervention program before six months of age. However, by Year 3 of this grant WE-TRAC will also be capable of collecting and reporting the number of babies enrolled in both the GBYS Program as well as the

State's Birth-3 Program. The WSB Program will also report the number of members involved with the Wisconsin Chapter of Families for Hands & Voices. The number of infants with a medical home will be a greater challenge to quantify. The WSB Program will identify the number of babies who have medical home information provided in WE-TRAC. The MCHB required National Performance Measures will also be reported.

IDENTIFICATION OF TARGET POPULATION

The target population of WSB Program and this grant is all newborns born in Wisconsin, their families, the neonatal service providers who screen for hearing loss, primary and specialty care providers, audiologists, and IDEA Part C and B providers. While Wisconsin has made excellent progress in implementing UNHS in 100 of the 102 birthing facilities without a legislative mandate, there remains the need to implement UNHS programs in place the two remaining hospitals without a UNHS program. The WSB Program in collaboration with the Wisconsin Perinatal Foundation implemented a matching grants program to assist small hospitals with the purchase of screening equipment and the establishment of screening programs. A similar strategy will be utilized for the two remaining hospitals as they are rural with less than 50 births.

Maintenance of quality hospital screening programs with established follow-up procedures remains an issue. From past hospital surveys it is estimated that half of hospitals have mechanisms in place to track that infants who failed a re-screen were seen in follow up by an audiologist and referred for intervention services. Information gathered from the WE-TRAC pilots indicates that this web based tracking and follow up system can be a valuable tool to hospital staff and the WSB Program staff to assure timely follow up. In addition,

implementation of established screening and follow up protocols, regular contact with hospitals, and monitoring of referral rates is necessary to maintain quality screening programs.

Providing UNHS for the approximately 900 home births in Wisconsin is an important issue. The WSB Program Director obtained private funding to purchase portable screening equipment and implemented a UNHS screening project with midwives in areas of the state with a high incidence of home births. In this project midwives reported screening results initially by paper and then by entering screening results on the blood card and utilizing WE-TRAC. Among home births screened there have been none lost to follow-up. Lack of funding for screening equipment, and barriers to follow-up, especially among select cultures, restricts the growth of the homebirth project. The WSB Program Director continues to work with the DPH Perinatal Homebirth Committee to address this issue.

This project targets medical home providers and specialty providers, audiologists, and IDEA Part C and B providers who are part of the EHDI continuum. Comprehensive audiologic and medical evaluations are required to manage the infant when a hearing loss is suspected and confirmed. Barriers identified include: lack of skilled pediatric audiologists in all areas of the state, lack of pediatric specialty providers with knowledge of hearing related issues, lack of knowledge of hearing issues by all physicians, and lack of resources to support appropriate evaluations.

Local Birth-3 Programs are administered at the county level (72 counties) with oversight by the state Birth-3 Program. The challenges experienced by the Birth-3 Program are a lack of an array of skilled hearing intervention services in most areas of the state and inadequate funding for early intervention services. In partnership with the state Birth-3 Program, WSB established a multi-disciplinary consultant network to assist local the Birth-3 Programs and has recently

provided capacity building mini-grants to county Birth-3 Programs to improve current and future services for d/hh children. Work will continue to expand the capacity of local programs and to assure families have an array of quality services.

Most importantly, this project targets children who are deaf or hard of hearing, their families, and the organizations that provide them support and information. One area of focus for this project will be to provide resources to families that are easily understood and respectful of culture. In addition, the WSB Program believes that access to other families and culturally competent, family-centered support services are an essential component of the EHDI service system and an effective means to reduce the number of infants lost to follow-up.

The goals and objectives outlined in this application will address the identified needs of the target populations of this grant.

GOALS AND OBJECTIVES

The WSB Project Work Plan and Logic Model *(Appendix A5 & A6)* describes goals and objectives, inputs, activities, and timeline for each objective listed.

PROJECT METHODOLOGY

Goal 1: Screen **all** babies for hearing loss prior to discharge from the hospital.

Objective 1: Assure that 100% of hospitals are screening babies prior to discharge. While Wisconsin has made excellent progress in implementing universal screening programs in 100 of the 102 birthing facilities, two rural hospitals with less than 50 births per year continue to utilize the high risk register to screen infants for hearing loss. Nurse Managers at each hospital identified lack of funding as the primary reason for not implementing UNHS. The WSB Program Director will meet with each hospital to educate them on the components of a successful UNHS program, assist staff in assessing their internal resources, brainstorm potential

community partners, and discuss the potential for matching grants. The WSB Program in collaboration with the WSHA/EHDI Ad Hoc Committee will assist hospitals in securing funding by developing a funding proposal. This funding proposal may be utilized by the remaining hospitals to approach foundations, hospital auxiliaries, service clubs and other potential funding sources. The proposal will also be utilized by the WSHA/EHDI Ad Hoc Committee and WSB Program Director to request matching funds from the WSHA Foundation. Once funds are secured, grant applications will be developed and distributed to the two remaining hospitals to purchase hearing screening equipment. The WSB Program Director will continue regular contact with the hospitals to assure successful implementation of UNHS protocols and Technical Assistance (TA) will be provided as needed.

Objective 2: Assure that all hospitals adhere to Quality Assurance guidelines as they apply to screening and refer rates.

It is important that hospitals not only implement UNHS Programs, but that they are screening 100% of babies prior to discharge, while keeping refer rates less then the AAP recommended 4% referral rate. Wisconsin's refer rate has been consistent at around 1.8%. However, it is important that TA is available to hospitals with rates that seem too low as well as too high. Quality Assurance guidelines will be developed to guide TA and outreach efforts to hospitals. The WSB Program in collaboration with the WSHA/EHDI Ad Hoc Committee will establish quality assurance guidelines for hospital screening programs, which will help to define which hospitals need TA. The committee will first review existing guidelines used by other states, as well as manufacturer guidelines. A "Quality Assurance Guideline" document will be developed to be shared with hospital UNHS programs. Screening and refer rates will then be monitored for

adherence via the WE-TRAC System. WSB staff will provide TA to those hospitals not meeting these guidelines.

Goal 2: All babies who do not pass the hospital screening will receive thorough diagnostic services by three months of age.

Objective 1: Follow-through rates will be assessed between hospital and audiology systems.

According to CDC data only half of newborns who do not pass the hearing screen are known to receive an audiologic evaluation. WE-TRAC, Wisconsin's data collection, tracking and referral system, was piloted with ten birthing hospitals. The hospitals varied in size, NICU capacity, rural/urban location, screening and referral protocols and relationships with audiology. Pilot hospital data, representing approximately one fifth of Wisconsin births, was collected for approximately one year and saw a lost to follow-up rate of less than 10%.

Phased roll-out of the enhanced production WE-TRAC will begin in January 2005 with the initial pilot hospitals. When all ten hospitals and associated audiologists are actively using WE-TRAC, lost to follow up rates will be assessed to provide baseline data. Assessment will be done initially through careful monitoring and manual calculations using the WE-TRAC system. The WSB program will work with the WE-TRAC developers to design and implement lost to follow up reporting functionality. By March 2006, Statewide lost to follow-up rates will be determined utilizing WE-TRAC reports. An initial increase in the percent lost to follow up is anticipated when the WE-TRAC system is implemented statewide.

Objective 2: Families will have a stronger understanding of the importance of follow-through at the time of screening and how to access it.

The National Institutes of Health convened a panel of experts to identify problems associated with loss to follow-up. The kind of information given to parents about follow-up and the method in which it was given are two identified barriers. Currently, there is no standardized method for informing parents about follow-through, nor is there consistent follow-up materials provided to parents at the time of screening.

A Follow-Through Work Group will be assembled to assist in the development and implementation of program activities, strategies, and materials to decrease lost to follow-up. One focus will be increasing parental understanding of the importance of follow-up.

Parents of deaf and hard of hearing children who are already serving as Parent Guides with the GBYS Program will receive additional training on how to make phone calls to parents after their baby refers. This expansion of the Guide-By-Your-Side (GBYS) Program will be provided through a contract with WESPDHH *(Appendix D1)*. This will be called the GBYS Follow-Through Program. Consent will be needed to participate. The Follow-Through Work Group will assist in the development of three materials; a Talking Points Guide for Nurses, "Follow-Through Card", and a referral form. The Talking Points Guide will assist nurses in discussing the screening results and the Follow-Through Program. The card will inform families about their parent guide and contact information. The referral form will gather parent contact information and consent. The referral form will be sent to the WSB Program Director who will then notify the Parent Guide to contact the family as soon as possible. The Follow-Through Parent Guides will: a) stress the importance of following up; b) assist with follow-up appointment; and c) problem solve any barriers to follow-up *(Appendix A7)*.

Objective 3: Develop statewide referral networks of Early Hearing Detection and Intervention Stakeholders

The NIH also identified "Lost messages" and ineffective communication as barriers to follow-up. Hospital staff must communicate the need for follow-up to the family, but also to the baby's physician or medical home and the audiologist responsible for conducting the follow-up procedure. Improving communications and relationships between community providers will be a focus of this project.

The WSHA/EHDI Ad Hoc Committee will develop and implement a series of mini-grants that will bring together multidisciplinary groups of providers to implement a plan to reduce the number of babies lost to follow-up in their community. The WSHA/EHDI Ad Hoc Committee will assist in developing an application guidance. Applicants will need to come together to develop their "action plan" to include in their application. Applications must demonstrate: commitment to decreasing lost to follow-up rates; buy-in from other provider communities; willingness to improve cross-system communication; dedication to implementation of their action plan; and intention of including the GBYS Follow-Through Program in planning. WSB staff will provide TA to potential applicants.

Applications will be reviewed by the WSHA/EHDI Ad Hoc Committee, and evaluated for the number and variety of organizations collaborating together on the grant, and the potential impact of their action plan. Grant amounts will vary ($500-$1,500) based on number of organizations represented in the application. When applicants have been selected, mini-grant awards will be administered through the WSHA Office *(Appendix D2)*. The WSB Program Director will be available for consultation to assist implementation of the action plan and will track lost to follow-up rates of the grantees. A second round of mini-grants will be offered in Year 2 of the grant. The WSB Program Director will continue to monitor year one grantees and will also be tracking lost to follow-up rates of the new grantees.

In Year 3, a Follow-Through Consortium will be organized and hosted through a contract with WSHA. This Consortium will be open to all EHDI providers. However, targeted outreach and encouragement to attend will be focused toward systems that are demonstrating high lost to follow-up rates. Mini-grantees will present successful strategies and lessons learned. Participants in the Consortium will be encouraged to network with others, and develop their own action plan for improving the lost to follow-up rates in their own organizations. Also at the Consortium, those grantees who have demonstrated adherence to or improvement towards meeting the Quality Assurance Guidelines will be formally recognized. Through small mini-grants, providers will establish communication and strategies that can then be shared across systems statewide, at the same time publicizing the guidelines and recognizing the hard work and quality efforts of Wisconsin EHDI systems.

Goal 3: Assure that all children identified as deaf or hard of hearing receive comprehensive early intervention services and smooth transition into appropriate early childhood education services.

Objective 1: Develop a uniform referral mechanism to early intervention services.

The Birth-3 Program prepared a statement clarifying eligibility criteria and responsibilities for infants and toddlers with hearing loss. The eligibility statement indicates that any child with a confirmed hearing loss regardless of degree or configuration, can be found eligible by the early intervention team. This information has been made available through a variety of means, however, the number of deaf and hard of hearing children receiving intervention services has not significantly increased as reported by the State Birth-3 Program. The Birth-3 reporting system may not be an accurate measure since Birth-3 Programs must only identify the child's primary

diagnosis for receiving services. This may result in under reporting of children who are both deaf and hard of hearing and have another condition.

The WSHA/EHDI Ad Hoc Committee in conjunction with the WSB program has developed a CHL. The CHL form was initially piloted with six audiology clinics. Feedback was gathered on the content, organization and format of the form. Most of the audiologists indicated that they would rather have the reporting and referral form in a fillable, electronic format. Since June 2004, the CHL form is available as an electronic form in WE-TRAC. The WSB Program Director has encouraged audiologists to use the CHL to make referrals to Birth-3 programs. The WSB program has also met with county Birth-3 programs and encouraged them to request the CHL form when receiving a referral from an audiologists. The WSB Program will continue to promote the importance of using the CHL form at trainings, WSHA meetings, and through personal outreach, as a mechanism to reporting and referral.

Objective 2: Increase referrals and follow-through to county Birth-3 Programs.
The GBYS Program matches a family who has just learned of their child's hearing loss with an experienced parent of a deaf or hard of hearing child (Parent Guide). The Parent Guide makes up to three home visits with the family to provide emotional support, answer questions, and provide unbiased information and resources. The Parent Guide will try to contact the family within 24 hours of receiving the referral and make the first home visit with the family within two weeks. The last home visit is made in conjunction with the Birth-3 provider. The Parent Guide will complete the Services Summary form. This relationship and coordination will help to assure that families are connected to early intervention services and that a smooth transition is made from the GBYS program to the Birth-3 Program. Bilingual Parent Guides, currently working statewide, increase the liklihood of those at higher risk for lost to follow-up (due to language and

literacy barriers) by conveying important information in their primary language from another parent who has found the early intervention system beneficial.

Objective 3: Increase the capacity of early intervention programs to offer approprite, comprehensive services to families of deaf and hard of hearing children.

WSB in collaboration with WPDP offered mini-grants in September 2004 to county Birth-3 Programs to assist in meeting the current and future needs of infants and toddlers in their counties who are deaf and hard of hearing, and their families.

Mini-grants focus on increasing positive outcomes, especially as it pertains to the promotion of language and social emotional development in young children who are deaf or hard of hearing. Applicants were encouraged to demonstrate collaboration across programs, agencies and systems statewide, including GBYS and WESPDHH.

An early intervention summit will be sponsored by WESPDHH. Year 2 grant funds will be used to support co-sponsorship from WSB and will support the time and travel of national experts who will speak at the summit. This four-day summit will be open to providers and families during the first two days. National and local experts will introduce research that supports best practices for early intervention of young deaf and hard of hearing children. The mini-grantees will also present on the outcomes of their mini-grants. State leaders, parents will be invited to participate in the last two days of the summit. The national experts will facilitate discussion related to strategies for implementing best practices in early intervention in Wisconsin and help state leaders develop a plan for future directions.

Goal 4: Assure family's awareness of family support organizations.

Objective 1: Educate providers about family support opportunities.

Research has demonstrated that parents who connect to another family with a child who is deaf or hard of hearing report better bonding with their baby, and more effective early intervention experiences.

Through outreach, site visits, formal presentations, and exhibits at conferences the WSB Program will educate providers about family support organizations as well as including parents as presenters whenever possible. WSB will utilize contacts with providers to spread the word about family support organizations such as Wisconsin Charter of Hands & Voices will increase the likelihood that newly identified families will gain access to these valuable resources.

Objective 2: Increase parent support opportunities by supporting parent leadership initiatives.

WSB will continue to advocate for parent support opportunities. WSB in collaboration with WPDP is planning a conference series called *Parents as Leaders(PALS)* training that will be specifically target parents of deaf and hard of hearing children *(Appendix F-b)*. PALS is funded by the State Birth-3 Program.

WSB will also support parent leadership initiatives such as the annual conference for families. This conference is chaired by a parent and planned by a committee of parents with the support of the WSB Program Coordinator and the WESPDHH Program Director. A mentorship model for conference planning is established where the conference chairperson is paid to be involved for two consecutive years. During the first year as the assistant chair they learn responsibilities, organization and delegation skills, and timeline so that by Year 2 they can successfully act as the Conference Chair and mentor. The conference chair maintains and updates a conference planning binder to pass along lessons learned from their experience to the next chairperson. This promotes leadership skills and infuses parents with confidence. Also, by

encouraging families to plan the conference they will choose educational sessions necessary to enhance their knowledge base and advocacy skills, rather than having professionals guess at what they need to learn. For example, during planning of the first conference for parents held in June 2003, the parent committee chose to sponsor the National Chapter of Hands & Voices to learn more about starting a parent advocacy group. On September 19, 2003 the first board meeting of Wisconsin Hands & Voices was convened. The third annual conference for families is scheduled for March 11-13, 2005.

WSB will also contract with the Wisconsin Chapter of Hands & Voices to fund parent participation in the Annual EHDI Conference *(Appendix D3)*. This conference provides a wealth of information, resources, and connections to parents from other states. To further enhance parent support initiatives WSB will contract with Hands & Voices to organize a parent to parent event that will increase knowledge of the parent support organization and recruit additional parent leaders.

Goal 5: Assure that every child that does not pass the hospital screening has an informed medical home.

Objective 1: Education and outreach regarding the role of the Medical Home in hearing screening follow-up and after a patient has been diagnosed as deaf or hard of hearing. Despite frequent targeted outreach to primary care providers through journal articles and targeted mailings, reports from families continue to be shared with the WSB Program of parents expressing concern about their child's hearing to their primary care physician, only to be met with an unenthusiastic "wait and see" or an even more worrisome "Don't worry, they can't have a hearing loss. They passed their hearing screening." The EHDI Implementation Work Group's Physician Education Committee identified strategies to inform providers including creation of

office materials. Grant funds will be used to design, print, and distribute a poster targeted to families that will be placed in physician waiting rooms. The poster will be designed to be very simple with three key messages: It is never too early to test a babies hearing; Did your baby pass the hearing screening? If you don't know ask your doctor; Early intervention makes a difference, the earlier you find out the better. The purpose of the poster will prompt parents to ask questions and initiate discussion with their physician about their baby's hearing. The poster will also serve as a reminder to the physician that a baby's hearing status is important. The poster will be developed by the WSB Program Director with feedback elicited from parents, providers, and the EHDI Implementation Work Group. The posters will be printed in English, Spanish and Hmong. They will be widely distributed to physician's offices through mailings and personal deliveries by parent volunteers. Posters will also be disseminated to local public health departments, community clinics, Headstart programs, WIC Clinics, and other places that are frequented by families and children.

WSB will continue to promote to physician/medical home "Just-In-Time Information" letter at the time of confirmation of hearing loss. This letter, along with a modified version of the AAPs EHDI Checklist for Providers, is available on the WE-TRAC Forms tab and can be personalized to include the baby's name as well as information about the audiologist who is sending it. Audiologists will be encouraged throughout this grant period to include the "Just-In-Time Information" with their report that they routinely send to the baby's physician.

Objective 2: Develop and market a physician module in WE-TRAC.

Changes to the WE-TRAC system will support physician participation. A place on the child's chart to enter child's address and PCP/Medical Home information, as well as persistent reminders from the system to complete PCP information will be added. WE-TRAC will also

keep an address history to assist providers in locating families that have not followed through on the follow-up appointment. Users will be able to set up e-mail notification for events such as one week before "time-out" or a new baby on the queue. An automatic email will be generated to the baby's primary care physician in the case of a refusal of hearing related care. WSB will work with physicians to identify other features that would encourage their use of WE-TRAC to actively manage the children in their practice with hearing loss.

Goal 6: Establish a comprehensive follow-up and tracking system statewide.

Objective 1: Promote the active use of the WE-TRAC System.

WE-TRAC contains tracking and referral processes that clearly show the transfer of responsibility for follow-up from one provider to the next for each point of referral or action. Infants' names appear in organization "queues" with a description of the next procedure and a date by which it should be completed next to each name. System alerts and reminder notices are sent to the provider if no action is taken by this date, and the WE-TRAC administrator's will be alerted for follow-up. The WE-TRAC administrator can also view a list of children currently identified as lost to follow-up. Strengthening the safety net assuring timely and appropriate coordination of care through the EHDI continuum is a priority as WE-TRAC development continues.

With the release of WE-TRAC in 2005, there will be a phased regional roll out to systems of hospitals and associated audiology clinics, beginning with organizations who piloted the initial version.

Objective 2: Complete development of the system to allow for comprehensive follow-up monitoring through early intervention.

WSB has conducted six county Birth-3 site visits to gather requirements for use of a WE-TRAC early intervention module. During this grant cycle WSB will continue work with the GBYS program and early intervention programs to develop the early intervention module, which will include the WE-TRAC standards of alerts reminder notices, and clear transfer of responsibility. Selected early intervention programs, representing rural and urban communities as well as touching state boundaries, will pilot the early intervention module. WSB will also outreach to bring PCP users, and establish additional PCP/Medical Home notifications based on PCP feedback (i.e., at outpatient screen referral).

WSB will analyze trends and patterns in lost to follow-up through-out this grant cycle. Reports that show users a snapshot of infants screened, referring, returning for follow-up screen, and diagnosed with hearing loss for their facility and statewide are currently being developed. Recommendations for future WE-TRAC development include real-time reports. During this grant period, WE-TRAC reports showing lost to follow-up data will also be developed.

COLLABORATION AND COORDINATION

The success of WSB to date is in large part due to the collaborative effort of many private and public agencies. The EHDI Implementation Work Group and its subcommittees are example of strong collaboration with a wide variety of organizations.

When these partners were queried about their continued participation in the workgroup in 2004, the response was overwhelmingly positive. Some key examples of past collaborations with private partners include the Wisconsin Personnel Development Project (WPDP) as lead agency for Birth-3 consultant training, parent summit and future parent leadership training; Wisconsin Health and Hospital Association (WHA)- EHDI Implementation Work Group member and partner in developing hospital surveys; WSHA/EHDI Ad Hoc Committee

Implementation Work Group member, participation in the development of the CHL reporting form, pediatric audiology survey, pediatric audiology training, and future partnership with proposed mini-grants; WIAAP EHDI Implementation Work Group and subcommittees including member participation in the national meetings and involvement with the Hands & Voices "Better Speech and Hearing Month" awareness campaign; and Wisconsin Academy of Family Practice (WAFP)- EHDI Implementation Work Group member, support in distribution of outreach and educational materials for family practice providers. A recent partnership has been established with the Wisconsin Educational Services Program for Deaf and Hard of Hearing Students – Outreach (WESPDHH). Discussions with WESPDHH led to the application for a DPI Preschool Options Discretionary Grant funds to be used for the GBYS Program and is coordinated through a joint WSB / WESPDHH effort. The Interactive Notebook for Families was used as part of the GBYS training curriculum. Although this parent resource was initially developed through WSB funds, WESPDHH has agreed to sustain this resource by reprinting and translating it into Spanish.

ADMINISTRATION AND ORGANIZATION

The WSB Program is located in the Family Health Section (FHS) in the Bureau of Community Health Promotion (BCHP) in DPH, DHFS *(Appendix E, Organizational Chart)*. In September 2004 a reorganization of the DPH was approved. This reorganization strategically places the WSB Program in the FHS. A new team was created called "Early Screening". The team includes Genetics Services, the Metabolic Screening Program, and the WSB Program including the WE-TRAC Project. Programmatically team members report to the CSHCN Medical Director and are supervised directly by the FHS Supervisor. Other programs within this

section include the Title V MCH and CSHCN Programs and the Birth Defects Surveillance Program.

This organization and management structure was created to positively impact data collection efforts as well as the coordination and integration of the screening/surveillance programs (hearing, metabolic, and birth defects) with support and services (genetic services, Title V funded Regional CSHCN Centers, Wisconsin Medical Home Learning Collaborative). The CSHCN Medical Director serves on the Title V Needs Assessment Steering Committee and has responsibility to assure that the Wisconsin Sound Beginnings Program's activities, reports, and outcomes are incorporated into the Block Grant needs assessment, application and report. In addition, the WSB Program reports annually to the Legislature on its work *(Appendix A-b)*.

As part of the DPH reorganization, the Bureau of Health Information (Vital Records) relocated to the DPH and a new bureau was created called Health Information and Policy that includes the PHIN and a Project Manager for PHIN Project Integration. This structure will enhance the Division's ability to integrate data systems such as WE-TRAC, a Project Area Module (PAM) of the PHIN.

Other key programs located within the Department that the WSB Program works closely with include: the Birth-3 Program and the Wisconsin Office for the Deaf and Hard of Hearing in the Division of Disability and Elder Services and the Title XIX Program and SCHIP (Badger Care) in the Division of Health Care Financing.

ORGANIZATION EXPERIENCE, CAPACITY AND AVAILABLE RESOURCES

The FHS administers the Title V MCH/CSHCN Block Grant for Wisconsin and awards statewide and regional projects to address important maternal and child health issues and system development such children with special health care needs, birth defects surveillance, and genetic

counseling services. The FHS has oversight responsibility for meeting the Title V Block Grant National Performance Measures including "early and continuous screening".

The CSHCN Program in the FHS funds five Regional CSHCN Centers located in each of the DPH regions to provide information, referral, and follow-up services, parent-to-parent support, and service coordination to families. This program grew out of a needs assessment suggesting that services to CSHCN would be improved by a regionally based system.

The FHS also administers the toll free First Step Hotline and website, Wisconsin's 24 hours a day, 7 days a week information and referral service dedicated to helping families and professionals find services for children birth to 21 years with special needs. First Step is funded in collaboration with Title V and the Birth-3 Program in the DDES.

The CSHCN staff represents a broad array of experienced health care professionals who will be involved in this program including individuals with expertise in deaf and hard of hearing services and experience in data collection, analysis, and data integration.

XI. Appendix

Appendix A. Tables, Charts, etc.

1⬥WSB Overview
2⬥Confirmed Hearing Loss (CHL) Form
3⬥EHDI Workgroup Advisory Committee
4⬥Services Summary Form
5⬥Work Plan
6⬥WSB Program Logic Model
7⬥Parent Guide Follow-Through Flow
Additional Tables, Charts, etc. Available Upon Request
a⬥UNHS Program Model; b⬥Legislative Report

Appendix B. Job Descriptions for Key Personnel

1⬥WSB Program Director
2⬥EHDI Follow-Up Coordinator
Additional Job Descriptions Available Upon Request
a⬥State Lab of Hygiene Staff; b⬥Regional Parent Guide; c⬥Bilingual Parent Guide; d⬥Birth to Six Services Coordinator

Appendix C. Biographical Sketches of Key Personnel

⬥Sharon Fleischfresser, ⬥Lila Katcher, ⬥Elizabeth Seeliger
Additional Biographical Sketches Available Upon Request
⬥Sally-Ann Anderson; ⬥Karen Kennedy-Parker; ⬥Roni Mack

Appendix D. Letters of Agreement and/or Description of Proposed/Existing Contracts

1⬥Preliminary WESP negotiations
2⬥Preliminary WSHA negotiations
3⬥Preliminary Hands & Voices negotiations

Appendix E. Project Organizational Chart

Appendix F. Other Relevant Documents

1⬥State and Local Indirect Cost Agreement
2⬥GBYS Brochure
Additional Relevant Documents Available Upon Request
a⬥Parent Conference Flyer
b⬥Parents As Leaders (PALs)
Letters of Support:
-Wisconsin Families for Hands & Voices
-Wisconsin Educational Services Program
-Wisconsin Speech-Language Pathology and Audiology Assoc (WSHA)
-Wisconsin Birth-3 Program, Division of Disability and Elder Services
-Wisconsin Chapter-American Academy of Pediatrics
Additional Letters of Support Available Upon Request:
-University of Wisconsin Division of Information Technology (DoIT)
-University of Wisconsin Waisman Center
-Center for the Deaf and Hard of Hearing (CDHH)

WSB Work Plan Logic Model

Resources Inputs	Outputs		Outcomes		Tracking/Evaluation
	Activities	**Participation**	**Short-term**	**Long-term**	
Staff • WSB Program Director Partners • WSHA/EHDI Ad Hoc Committee • WHSA Foundation • Community Service Clubs	• Meet with staff from 2 hospitals to discuss UNHS program strategies by 6/2005 • Develop funding proposal for foundations, hospital auxiliaries, service clubs and others by 12/2005 • Utilize funding proposal to attain WSHA matching grant funds • Develop matching grants to hospitals to purchase hearing screening equipment by 6/2006	– 2 remaining birthing hospitals – Families who will benefit from having the UNHS program in place	Objective 1: Assure that 100% of hospitals are screening no less than 95% of babies prior to hospital discharge	Goal 1: All babies will be screened for hearing loss prior to discharge from the hospital by 3/15/08	– WE-TRAC – Funding Secured
Staff WSB Program Director EHDI Follow Up Coordinator Partners • WSHA/EHDI Ad Hoc Committee • Equipment Manufacturers • Hospital Partners	• Establish Quality Assurance Guidelines for hospital screening programs • Review existing standards with Ad Hoc Committee 10/2005 • Best practice document created by 3/2006 • Provide technical assistance to those hospitals who do not meet the Quality Assurance Guidelines - ongoing	– Birthing hospitals – NICUs	Objective 2: Assure that all hospitals adhere to Quality Assurance standards as they apply to screening and refer rates		– Quality Assurance "best Practice" standards will be documented and distributed to hospitals by 3/2006 by WSB Program Director – Monitor hospital compliance with quality standards via WE-TRAC reporting beginning 4/2006-ongoing by EHDI Follow-Up Coordinator
Staff • DPH Epidemiologist • WE-TRAC Project Manager • Follow-Up Coordinator • WSB Program Director	• Assess the status of UNHS loss to follow-up rates in pilot hospitals 07/01/05 • Assess the statewide status of UNHS loss to follow-up rates 4/01/06-ongoing	– 10 WE-TRAC Pilot Hospitals – Remaining 94 birthing hospitals in Wisconsin	Objective 1: Follow-through rates will be assessed between hospital and audiology systems	Goal 2: All babies who do not pass the hospital screening will receive thorough diagnostic services by 3 months of age	Report Compiled
Staff • WSB Program Director • WESPDHH Funds • MCHB Grant Funds Partners • Follow-through Work Group • Hands & Voices	• Convene Follow-through Work Group by 05/01/05-ongoing • Develop materials relating to follow-through program (i.e. follow-through card, talking points for nurses, referral form) by 07/01/05 • Identify and train Follow-Through Parent Guide by 08/01/05 • Identify and address pertinent barriers to follow-up 10/01/05 -ongoing	– Hospitals – Audiologists – Early Intervention – Families – Parent Guides – Hands & Voices – WESPDHH – WSB Program	Objective 2: Families will have a stronger understanding of the importance of follow-through and how to access it		– Materials developed and distributed – Guides hired, trained, and ready to make follow-through phone calls – Send survey to families to assess effectiveness of Follow-through Program

Resources Inputs	Outputs		Outcomes		Tracking/Evaluation
	Activities	Participation	Short-term	Long-term	
Staff • WSHA/EHDI Ad Hoc • Committee • WSB Program Director • WSHA Office Staff Money • Year 1-3 of MCHB Grant • Subcontract with WSHA Partners • WSHA/EHDI Ad Hoc Committee • Wisconsin Chapter–AAP • WHHA	• Develop and release mini-grant application guidance 07/05-08/05 • Administer first round of mini-grants to systems by 10/31/05 • Administer second round of mini-grants to systems by 10/31/06 • Provide formal recognition to systems who have maintained QA standards by 10/15/07 • Organize and host Follow-through Consortium to share lessons learned and demonstrate success to other systems by 10/15/07	– Providers – Pediatricians – Family Practice Physicians – Nurses – Hospital Administrators – Audiologists – Early Intervention Staff – Parent Guide Follow-Through Coordinators	Objective 3: Develop statewide referral networks of Early Hearing Detection and Intervention Stakeholders		Evaluate benefit of meeting through participant survey and action plan
Staff • WSB Program Director • State Birth-3 Program • Birth Defects Program Coordinator • WE-TRAC Project Manager	• Work with Audiologists to promote use of CHL Form for referrals to Birth-3 Services - onoing • Distribute at trainings and WSHA meetings, personal outreach by 12/2005 and ongoing • Promote the importance of referrals to Birth-3 Services • Create link in WE-TRAC to CSHCN/ Birth Defects Prevention Referral Website by 3/2006	– Pediatric Audiologists – Early Intervention Providers	Objective 1: Develop a uniform referral mechanism to early intervention services (B-3 and GBYS)	Goal 3: All children will be identified and receive comprehensive early intervention services and smooth transition into appropriate early childhood education services	– Usage of CHL forms will increase WE-TRAC audiology users – Demonstrate an increase in the number of d/hh children enrolled in EI Programs
Money • DPI Preschool Options Discretionary Grant Staff • WESPDHH • Parent Guides • WSB Program Director • State Birth-3	• Use Guide-By-Your-Side program to assist families in connecting with B-3 Programs 4/2005 -ongoing	– Families – Parent Guides – Local Public Health – Early Intervention	Objective 2: Increase referrals and follow-through to B-3 Programs		– Survey B-3 Programs to assess their perception of the benefits of the GBYS Program – Services Summary Data will be compiled and tracked
Staff • WPDP • State Birth-3 Program • WSB Program Director • WESPDHH Money • WESPDHH • MCHB Grant	• Administer mini grants to county B-3 agencies currently working with a d/hh child to enhance service delivery by 9/01/06 • Organize a EI Summit to develop an action plan for enhancing B-3 services for d/hh by 9/31/06		Objective 3: Increase the capacity of early intervention programs to offer comprehensive EI services to families of deaf or hard of hearing children		– Demonstration projects will exhibit at the EI Summit – Training completed and evaluated – Statewide action plan is documented

Resources Inputs	Outputs		Outcomes		Tracking/Evaluation
	Activities	Participation	Short-term	Long-term	
Staff • WSB Program Director • WI - AAP • WAFP • WSHA	• Have support organizations speakers present at Audiology and B-3 meetings at every opportunity 4/2005-ongoing		Objective 1: Educate providers about family support opportunities	Goal 4: Assure parental awareness of family support organizations	Gather feedback from presentations and presenters

Staff
• WESPDHH
• WSB Program Director
Partners
• Hands & Voices
• FACETS
• WPDP
	• Support parent leadership initiatives
	  • PALs
	• Spread the word about the parent list serve and continue to list training opportunities 4/2005 –ongoing
	  • Parent Conference
	  • Hands & Voices
		– Audiologists
		– Early Intervention
		– Physicians
		– Hands & Voices
		– Parents
			Objective 2: Increase parent support opportunities by supporting parent leadership initiatives		– Coordinate presentations and analyze evaluations
					– Query organizations to determine if family awareness is growing
					– Monitoring of Parent listserve activity and usage will show increases

Staff • WSB Program Director • Hands & Voices Board • CSHCN Medical Director Money • MCHB Grant Partners • AAP Chapter • WAFP Champion • WSHA	• Create, print, and distribute culturally sensitive poster that encourage discussion of screening results and follow-through between new parents and their baby's physician by 3/31/06 • Assure that all physicians receive "Just-In-Time Information" soon after a child in their practice receives their confirmation of hearing loss by 03/31/07	– Parents – Providers – Community Clinics – Childcare centers – Physicians – Audiologists	Objective 1: Education and outreach regarding the role of the Medical Home in hearing screening follow-up and after a patient has been diagnosed as deaf or hard of hearing	Goal 5: Every child that does not pass the hospital screening will have an informed medical home	– Materials collected or created and distributed to physicians – Audiologists will be queried about distribution – Physicians will be surveyed to determine effectiveness

Resources Inputs	Outputs		Outcomes		Tracking/Evaluation
	Activities	Participation	Short-term	Long-term	
Staff WSB Program Director Follow-Up Coordinator UW-DoIT CSHCN Medical Director AAP WAFP **Money** CDC Grant	•	–	Objective 2: Develop and market a physician module in WE-TRAC		– Physician module piloted and implemented by 4/2007 – # of children with identified medical home will be tracked
Staff • Follow-Up Coordinator • WE-TRAC Project Manager • WSB Program Director	• Outreach and promote the use of the WE-TRAC system. All birthing units and Pediatric audiologists using WE-TRAC by January 2007	– Birthing Hospitals – NICUs – Audiology Clinics	Objective 1: Promote the active use of the WE-TRAC System by hospitals, pediatric audiologists and early intervention programs	Goal 6: A comprehensive follow-up and tracking system will be established statewide	Users will be registered and actively using the system
Staff • Follow-Up Coordinator • WE-TRAC Project Manager • WSB Program Director • State Birth to 3 Program ***Money*** **CDC Grant**	• Pilot WE-TRAC / EI module with 6 B-3 Programs by 4/1/07. • Work with all other EI service programs to interface with the WE-TRAC system by 3/31/08	– Early Intervention – GBYS Program	Objective 2: Complete development of the system to allow for comprehensive follow-up monitoring through early intervention	Through the use of WE-TRAC, providers will have a clear understanding of which babies need follow-up and for what	

Staff
• Follow-Up Coordinator
• WE-TRAC Project Manager
• WSB Program Director
• UW-DoIT
	• Develop functionality, ie:
	  • Case add function
	  • iterative reporting
	  • other identified enhancements by 3/31/08
	• Work with EI programs to utilize WE-TRAC
					Pilot new functionality with users. Gather feedback.