

## **Program Narrative**

### **Summary Progress Report for the period 4-1-09/3-31-10**

#### **1) Summary of Project Accomplishments:**

##### **Significant achievements**

All birthing hospitals, free-standing birthing centers and children's hospitals conduct physiologic hearing screenings and report results to the Ohio Department of Health (ODH) as required under Ohio law. Ohio is in its fifth year of full implementation of universal newborn hearing screening (UNHS). For the period 1/1/2008 to 12/31/2008, 138,468 UNHS reports were received at ODH. This was 93 % of the estimated 149,245 reported births in calendar year 2008 and the data is considered to be provisional.

The ODH public health audiologists monitored and provided technical assistance to assure hospitals conducted UNHS per legislative requirements and maintained acceptable screening referral rates. A standard protocol developed by program staff is followed in reviewing each hospital's UNHS policies, procedures and staff trainings to ensure compliance with the rules governing UNHS legislation. The ODH audiologists provided ongoing technical assistance and monitoring of all of the approximately 130 hospitals birthing and children's hospitals in Ohio via telephone and email. Additionally, they have provided more comprehensive and focused assistance to 21 facilities.

Significant achievements have been accomplished in UNHS compliance and quality assurance, UNHS rules revisions, consistency of communicating hearing screening results, standardization of conducting and reporting site visits, identifying and addressing factors leading to loss to follow-up and delays in enrollment into early intervention services.

**Barriers encountered and strategies utilized to overcome them**

Obtaining UNHS data results remained challenging. ODH continues to receive paper UNHS screening results forms from hospitals. Hospitals also enter the data from the UNHS screening results forms into the electronic birth certificate data system, Integrated Perinatal Health Information System (IPHIS). ODH Information Technology (IT) staff and a Public Health Researcher continues to extract data from IPHIS and import it into HI\*TRACK, a specialized UNHS software management program.

The ODH Infant Hearing Program staff continue to emphasize the need to link data from the electronic system (IPHIS) with the tracking software (HI\*TRACK) for program efficiency and accuracy. In July 2009, software and hardware revisions were implemented that extract all birth records from IPHIS and allow them to be imported into HI\*TRACK. For the first time since beginning to track UNHS, the Infant Hearing Program is able to access hearing screening results for *all* birth records in IPHIS. This software upgrade, along with the new IPHIS-generated hospital reports will enable the Infant Hearing Program Staff to monitor the hospitals and provide more timely feedback utilizing the web-based, “real time” HI\*TRACK software system. Plans include allowing the seven children’s hospitals direct access to enter hearing screening results and diagnostic evaluation results for at-risk and transferred infants directly into HI\*TRACK. Telephone conferences and technical assistance will continue if referral rates increase or if there are other issues related to compliance with the legislative mandate. This integration of data systems, still in its infancy, will allow for more efficient tracking, follow-up and subsequent interventions for the birth to three populations with diagnosed hearing loss or deafness.

ODH has emphasized that hospitals record a secondary contact phone number for the

infant's family if there is a non-pass screening result. Additionally, hospitals were contacted via telephone and/or email if there was missing information on the UNHS hearing screening report form. Some of the missing information can now be accessed by ODH staff through IPHIS, which saves time in completing records with missing information. Hospital compliance with requests to document the legal name of the infant, primary care provider information and caregiver contact information, all crucial elements for reducing the lost to follow up rate, continue to be a concern. Plans utilizing supplemental funding awarded in Fall, 2009 include additional hospital education utilizing a series of web-based modules.

## **2) Progress on Specific Goals and Objectives:**

**Goal I: All Ohio infants will receive hearing screenings before hospital discharge or within 1 month for home births.**

Objective 1: Hospitals will conduct newborn hearing screenings and send results to the Ohio Department of Health for all infants within the required time frame.

Activity: Monitor and provide technical assistance to assure hospitals and birthing centers conduct newborn screenings and send results to ODH,

Activity: Assure that hospital screening data is extracted from IPHIS

Activity: Work with hospitals to develop a Quality Assurance (QA) process to assess compliance

All birthing hospitals and freestanding birthing centers are required by law to screen babies prior to discharge and report UNHS results to ODH. ODH received UNHS reports on 93 % of babies born between 01/01/2008 and 12/31/2008. In accordance with Ohio legislation, hospitals perform a second hearing screening before discharge on all newborns that do not pass the first screening. Ohio UNHS rules were revised to be consistent with JCIH 2007

recommendations and all hospitals were provided with copies of the rule revisions and a summary of key changes in the spring of 2008. Birth information and screening results are entered by the hospitals into the State's Integrated Perinatal Health Information System (IPHIS). The UNHS information is regularly imported into HI\*TRACK, a software data management system for Early Hearing Detection and Intervention programs. Infants who transfer to children's hospitals or spend time in neonatal intensive care units do not have hearing screenings conducted until their condition is stable. After the hearing screening is conducted the results are sent to ODH and manually entered by data entry staff into HI\*TRACK for tracking and surveillance purposes.

All screening results are imported into HI\*TRACK. ODH continues to generate a referral listing of non-pass results, which is sent to each of the Regional Infant Hearing Programs for tracking and follow-up. All UNHS forms for out of state residents born and screened in Ohio are sent to the EHDI coordinator for the infant's state of residence for subsequent follow up according to their state guidelines.

ODH staff regularly monitor and provide technical assistance to assure that birthing hospitals, children's hospitals and free-standing birthing centers maintain UNHS programs, comply with state rules, and report results. If referral rates increase, the Audiologists initiate additional investigation and technical consultation. Development of a hospital wide quality assurance process was encouraged during Phase II visits and in a training DVD. Hospitals are currently reviewing their data and should have a monitoring process in place.

Objective 2: The statewide referral rate from UNHS will remain at four percent or less.

Activity: ODH staff will monitor hospital referral rates.

Activity: ODH staff will review hospital training processes for accuracy and cultural sensitivity.

Activity: Assure that hospital QA includes appropriate referral rates.

ODH Infant Hearing Program staff regularly monitor individual hospital referrals. Infant Hearing Program Staff review the UNHS referral reports prior to sending to the RIHP. With the upgraded HI\*TRACK, they can review individual hospital referral lists. A report of hospital referrals is also available through IPHIS. If there is a noticeable increase or decrease in referral rates the Audiologists follow-up and provide technical assistance to hospitals as indicated.

All hospitals were provided with targeted correspondence addressing specific items that needed to be completed on their screening results documentation in order to reduce loss to follow-up. Hospitals also received an electronic copy of the more broadly focused UNHS program newsletter.

Staff review hospital UNHS training processes to assure training for accurate testing, monitoring of screeners, and conveying information to parents in a culturally sensitive manner. Hospitals are educated about developing an internal QA process to monitor referral rates and to make necessary changes in the program if these rates increase. ODH consultants provided technical assistance for hospitals that need additional assistance with lowering referral rates.

The overall statewide average referral rate for the period 01/01/2008 and 12/31/2008 was 2.7 %, which is below the national standard of four percent (4%).

Objective 3: Local health departments will document that they distribute the ODH brochure about UNHS, obtain a signature for receipt of the brochure, and provide a list of audiology sites to parents of infants born at home.

Activity: ODH will educate local health departments (LHDs) about UNHS legislative requirements.

Activity: ODH will monitor distribution of UNHS parent brochures by LHDs.

Between fiscal years 2008 and 2009, ODH contacted each of the local health department registrars by phone to discuss UNHS legislative requirements regarding the role of the health department in providing information (ODH parent brochures) about newborn hearing screening to families who register a home birth. Boards of Health responsibilities include distributing the ODH parent brochure, to each family who registers a home birth, collecting a signature from that family for receipt of the brochure, and reporting to the Ohio Department of Health the number of brochures distributed. . Registrars are encouraged to provide families with a list of audiologists who perform newborn hearing screenings within a 60-mile radius of the family's residence. Last calendar year, of the total number of home births reported, 57% of families received the UNHS parent information brochure and of those receiving the brochure, 78% signed the form indicating receipt of the brochure. Submission of reports to ODH will continue on an annual basis.

***Goal II: All infants who do not pass newborn hearing screenings will receive diagnostic audiologic evaluations by age 3 months***

Objective 1: ODH Infant Hearing Program will track all infants who do not pass UNHS.

Activity: Extract and import IPHIS data into HI\*TRACK biweekly.

Activity: Extract referrals and send to Regional Infant Hearing Programs (RIHPs).

Activity: Enter non-pass evaluations into HI\*TRACK and generate reports.

As previously described, all hearing screening results are imported into HI\*TRACK and then into the UNHS referral spreadsheet. The referral spreadsheet is reviewed and then sent to each of the RIHPs for tracking and follow up. ODH Staff are working with the Hi\*Track Help Desk staff to automate referrals. ODH staff have started reviewing and ~~to~~ monitoring HT data entered by RIHPs for infant status via HI\*TRACK since September 2009.

Pediatric audiologists are required to provide ODH with copies of the diagnostic evaluation results for those infants that do not pass their hospital screenings. The diagnostic evaluations are reviewed by ODH staff and then faxed to the RIHPs. The RIHPs enter the data into HI\*TRACK and utilize it for tracking and follow-up of infants with a confirmed PCHL.

During the period of 01/01/2008 to 12/31/2008, a total of 3,681 infants did not pass UNHS and were referred to the RIHPs for tracking and follow up. In that same period, the RIHPs reported a total of 2,097 (57%) follow-up audiologic evaluations completed; 553 (14%) evaluations still in progress; 989 (27%) were infants lost to follow up (moved or, unable to contact); 118 (4%) diagnosed with hearing loss; and 59 (2%) where parents declined to have the audiologic evaluation. The above data provided is provisional, further analysis is needed on the data.

Objective 2: ODH will conduct focus groups to identify and/or formulate messaging that resonates with various audiences (e.g. parents, audiologists, physicians).

Activity: ODH will convene focus groups as needed and request their input on UNHS messages and dissemination.

Although no regional task forces were convened, OHD continues to request feedback from the Advisory Subcommittee. In the grant period they convened two short-term workgroups to address special issues. ODH provides technical assistance to the audiology community as requested or as needs are identified. Pediatric audiologists were included in the dissemination of the broadly focused program newsletter. Future plans include using supplemental funding for audiologist education and outreach.

ODH is using supplemental funding to provide Primary Care Provider (PCP) outreach for non-pass infants. Letters and protocols are being developed that will enable RIHPs to provide

the PCP of record with confirmation of hearing loss and regular reports of SKI\*HI expressive and receptive language development scores. The drafts will be shared with the members of the UNHS Advisory Subcommittee at the November meeting so that feedback can be incorporated into the final product.

Objective 3: Regional Infant Hearing Programs (RIHPs) will follow-up with parents of all infants who do not pass UNHS.

Activity: RIHPs will follow standardized protocol for outreach to identified families.

Activity: RIHPs will remain in contact with families until diagnostic evaluations are completed.

Activity RIHPs will maintain tracking records and submit semi-annual reports to ODH.

Activity: ODH will conduct monitoring and/or technical assistance visits at least annually or as needed.

ODH has nine regional subgrantees to coordinate and provide services in the local community for infants identified with hearing loss in all counties in Ohio. RIHP's follow standardized protocols for initial telephone contact with families and mail standardized letters to families they cannot reach by telephone.

The RIHP's remain in contact with families until diagnostic evaluations confirm any suspected hearing losses. Families of infants with confirmed hearing loss, a diagnosis of permanent childhood hearing loss (PCHL), are eligible to receive home-based habilitative services from the RIHPs. Services can begin immediately, with concurrent enrollment in Help Me Grow (Ohio's Part C early intervention program). Infant Hearing Program Consultants provide technical assistance via phone or emails as needed due to current travel restrictions. As of July 1, 2009 RIHPs are beginning to utilize HI\*TRACK to maintain and update all infant records electronically.

Objective 4: Personnel involved with UNHS will implement steps that may increase the follow-up by parents of infants who do not pass UNHS for timely audiologic evaluations.

Activity: ODH will convene regional task forces to identify and promote implementation of standardized measures.

Although regional task forces were not convened in this grant year, ODH will continue to provide outreach and education to hospitals, audiology professionals, medical providers, and RIHPs through telephone conferences, targeted messages, and newsletters. ODH plans to utilize supplemental grant funds in future years for targeted outreach to the audiology community.

Activity: ODH will monitor implementation of recommended practices.

The RIHP data staff are educated to encourage and assist families with scheduling the follow up evaluation. Hospital staff are also educated and reminded about the importance of the follow up component and timely follow up.

New hospital coordinators are provided with a basic orientation by the Infant Hearing Program Staff from ODH. Similarly, new hospital staff are required to go through internal hospital training and competencies testing prior to screening infants. ODH is planning to utilize supplemental funding to develop or purchase a series of web-based training modules.

Objective 5: Audiologists providing follow-up diagnostic evaluations for infants not passing UNHS will implement accepted diagnostic protocols as well as steps to increase parents keeping scheduled appointments.

Activity: ODH will disseminate materials from JCIH and national entities about diagnostic evaluation.

Activity: ODH will create and distribute materials listing recommended steps.

Activity: ODH will update the Audiology Directory annually and post it on the web.

Materials from NCHAM that include resources in Ohio, such as the Communicate with your Child Brochure, will be distributed to the pediatric audiologists to share with families that have an infant diagnosed with a permanent childhood hearing loss.

Audiologists, who perform evaluations on infants who do not pass UNHS, report the results of those evaluations to ODH using an ODH-created form (UNHS Follow-Up Hearing Evaluation Reporting Form). Infant Hearing Program Staff review all diagnostic follow up evaluation forms prior to faxing to the respective RIHPs.

Audiologists were referred to the evidence based American Speech Language and Hearing Association (ASHA) Guidelines for the Audiologic Assessment of Children from Birth to 5 Years of Age and the JCIH Year 2007 Position Statements in the revised Ohio rules effective May 2007. Individualized technical assistance was provided to clinical audiologists as needed.

ODH surveyed pediatric audiologists in 2007 and continues to regularly update the statewide Pediatric Audiology Directory as changes are received. The Directory is organized by county as well as by city, and includes screening and diagnostic information specific to each testing site. The Directory is available on the ODH website and each hospital coordinator and health department registrar was emailed a copy of the updated Directory in January, 2009.

ODH initiated a request for proposals and awarded a contract to “Enhance the Audiologic Evaluation Process for Infants Not Passing Universal Newborn Hearing Screening”. The overall goal is to expand follow-up diagnostic audiology services. By offering in home testing by an audiologist with a specific focus on increasing access to diagnostic audiologic evaluations for families who are not scheduling a follow-up evaluation for their non-pass UNHS infants, the number of infants seen by audiologists prior to 3 months of age would increase. Although the

study was small in scope, parental reasons for not scheduling a follow-up diagnostic evaluation included: 1) the doctor did not mention the UNHS test, 2) a general lack of follow-up, 3) the parents were told the screening is often inaccurate so not to worry, 4) the family did not carry insurance, 5) there was no available transportation and 6) the parents were unaware their child did not pass UNHS. Of those families participating in the home screening study, referrals were made for two children to Help Me Grow due to developmental concerns and 3 children were referred to their medical home for fluid in the middle ear,

**Goal III: All infants with confirmed hearing loss will begin early intervention and habilitative services by age 6 months**

Objective 1: Parents, physicians and audiologists will access the statewide programs for infants and toddlers with permanent childhood hearing loss (PCHL).

Activity: ODH will assure printed publications contain information about HMG and RIHP.

Activity: ODH will publicize website addresses about HMG and RIHP.

Activity: ODH will monitor referral sources to RIHP for infants with PCHL.

ODH publicized information about Help Me Grow and the Regional Infant Hearing Program in the revised UNHS parent brochure by adding more detailed information on Help Me Grow and the RIHP's and contact information, as well as on the website,

<http://www.ohiohelpmegrow.org>. RIHP brochures from every region contain the HMG logo and some basic information on HMG services. RIHP's also provide local outreach to various professional and parent groups emphasizing the collaboration of HMG and the RIHP. Ongoing outreach and presentations to the public and professionals emphasizes the collaboration of HMG and the RIHP.

A biennial UNHS Report to the Legislature is being finalized and will be another avenue for distribution of information on the UNHS program. The final document will be printed and distributed to the Governor's office, Ohio Senate, and the House leadership.

Objective 2: ODH will assure continuation of the Regional Infant Hearing Programs and their use of the SKI\*HI Curriculum.

Activity: RIHPS will continue to foster communications with the professional community to assure early enrollment and comprehensive EI services for families.

Activity: SKI\*HI training will be offered and used by parent advisors for family interventions.

Activity: ODH will monitor RIHP reports and Early Track (HMG) data system for enrollment in early intervention.

Activity: ODH will monitor parent satisfaction with RIHP services.

Regional Infant Hearing Programs provided outreach and education to physicians, audiologists, other Part C services, and community groups to emphasize the importance of early identification and to provide information on state programs and resources for families with infants and toddlers with hearing loss or deafness. Many of their outreach activities were curtailed beginning in July 2009 due to budget cuts. A more targeted outreach to the Medical Home or Primary Care Provider will be implemented in November 2009 utilizing supplemental funding.

All of the RIHP Parent Advisors have been offered SKI\*HI trainings. There are six (6) SKI\*HI certified trainers throughout the state. All parent advisors use the SKI\*HI Curriculum and offer weekly home visits and/or provide center-based activities for families of infants who are deaf or hard-of-hearing. ODH will determine the need for Basic SKI\*HI and Recertification

training. SKI\*HI training will be scheduled in the coming fiscal year for those parent advisors identified as needing training.

ODH audiologists will begin using HI\*TRACK to monitor RIHP programs on a quarterly basis to assure that families are enrolled in Early Intervention services. Infant Hearing Program and RIHP staff were provided access to Early Track, the HMG data collection system in July 2009, so RIHPs can check HMG records for enrollments of infants with PCHL and make electronic referrals to HMG for newly identified infants. RIHPs are also beginning to enter the semi annual SKI\*HI assessment results into HI\*TRACK. These results will be included in targeted outreach to the Primary Care Providers.

ODH developed and implemented a Parent Satisfaction Survey for RIHP services modeled after the EI Help Me Grow survey. The survey was distributed in Spring, 2009. The overall results indicate that each of the 16 questions received a 91% positive rating. Families are very satisfied with RIHP services and perceive these services as providing a tremendous benefit to their children and family members. Although most responses were very positive and many included unsolicited narrative, only 75% of respondents knew how to file a complaint. The RHIPs will be notified of the survey results after review by the Advisory Subcommittee.

**Goal IV: The Universal Newborn Hearing Screening Subcommittee will identify program gaps and will explore ways to address the gaps**

Objective 1: ODH will maintain broad representative membership on the UNHS Subcommittee

Activity: Applicants for the Subcommittee will be recruited with the assistance of professional agencies and organizations.

Activity: Subcommittee will consider geographic, experience, and group representation factors when recommending new members.

Professional make-up of the UNHS Advisory Subcommittee includes a wide range of professionals as mandated in legislative statute who are recruited throughout the state. There are currently vacancies for a hospital administrator, a representative of the insurance industry, and a family practice physician. The Subcommittee will be considering two candidates for the vacant neurologist position at the November meeting. The UNHS Subcommittee makes their membership recommendations based on geographic location, type of experience, and representative group of candidates when making appointment recommendations to the Medical Advisory Committee.

Objective 2: ODH will facilitate regular meetings of the UNHS Subcommittee.

Activity: Meetings will be scheduled quarterly.

Activity: Meetings will be accessible and interpreters provided.

Activity: Agendas will foster discussion of gaps and barriers.

Activity: Work groups will be formed as needed.

For the period April 2009 through November 2009, ODH coordinated two meetings of the Universal Newborn Hearing Screening Subcommittee. Meetings are held quarterly in Columbus in May, August, and November. The August meeting was cancelled and ODH staff will be meeting with the Subcommittee on November 6, 2009 to provide updates and solicit feedback on current initiatives. The next meeting is scheduled for February 2010. Interpreters are available at each meeting to facilitate communication for members of the deaf community. ODH provides programmatic updates at each of the meetings. The Subcommittee shares concerns, makes recommendations, and advises ODH of professional community challenges that needed to be addressed.

### **3) Current Staffing**

#### **Personnel**

The UNHS project supports the following Infant Hearing Program staff: a .5 FTE Consultant Audiologist, a .5 FTE Data Entry Clerk, a .25 FTE Audiology Student Intern, and a .25 FTE Supervisor. In addition, the project is supported by 2.4 FTE Consultant Audiologists, and the remaining .75 FTE of the Supervisor's time through federal Part C and other maternal and child health funding.

There has been no change in the permanent professional staff in the last year although an Audiology Student Intern who helped with review of audiologic evaluation reports and data entry graduated in June 2009 and another Intern will begin work in November 2009. The Program Supervisor is currently under the supervision of an acting Program Administrator and the acting Bureau Chief, due to the transition of Part C –Help Me Grow to the new Ohio Department of Education Center for Early Childhood Development.

### **4) Technical Assistance Needs**

ODH relies on the National Center for Hearing Assessment and Management (NCHAM) to provide current and correct data, to issue alerts regarding problems or advances related to the diagnosis and treatment of permanent childhood hearing loss, and to coordinate opportunities to increase knowledge and interact with experts as well as peers from other states. NCHAM Help Desk's expertise and technical assistance has been invaluable in training IHP staff so that they can assist the RIHPs with learning how to use the updated HI\*TRACK software. Two training sessions, in March and June 2009 were provided prior to the July, 2009 implementation and NCHAM Help Desk staff continue to assist IHP staff with creation of reports, setting up

customized letters, and testing ways to provide an accurate referral list so that the older software can be discontinued.

ODH relies on an internal technology support section, the Office of Management Information Systems (OMIS) for technical assistance and linkage to IPHIS. The OMIS staff extract IPHIS data and assist with import into HI\*TRACK. ODH BEIS has a staff of Public Health Researchers. One Researcher is assigned to the Infant Hearing Program to import data from IPHIS into HI\*TRACK for use by staff audiologists and RIHPs. The Researcher also analyzes data, tracks and corrects errors, and prepares annual reports. When the new HI\*TRACK is operating smoothly, more of the Researcher's time can be devoted to development and preparation of much needed program reports.

## **5) Collaboration and Coordination**

The Infant Hearing Program is located within the Bureau of Early Intervention Services (BEIS) at the Ohio Department of Health (ODH). ODH/BEIS is the lead agency for the Part C early intervention (Individuals with Disabilities Education Act) program. A strong relationship exists between Part C and Infant Hearing. The Part C program funds each county to provide early intervention services to families of infants and toddlers with developmental delays or disabilities. Part C funds also support the RIHP's which do follow-up and tracking of UNHS results as well as provide habilitative services. The services provided include a multidisciplinary evaluation and assessment, an Individualized Family Service Plan (IFSP), service coordination, family support and transition services.

Newborns, older infants and toddlers diagnosed with hearing loss or deafness are eligible by diagnosis for Part C services. In addition to Early Intervention Services through Part C, families of infants and toddlers with hearing loss or deafness are eligible for specialized services

from the Regional Infant Hearing Program (RIHP). As of July 1, 2010, the lead agency for Part C will be the Ohio Department of Education (ODE) and the Ohio Part C, Help Me Grow program will be integrated into the new Center for Early Childhood Education. There are many unresolved questions regarding the transition and IHP Staff are currently uncertain about the details of the plan and whether the RIHPs will continue as a separate ODH program to be fully funded via a transfer of funds from ODE.

In addition, ODH supports many programs through the Title V Maternal and Child Health Block Grant (MCHB) funds. The Infant Hearing Program collaborates with many of these programs. For instance, eligible children with special health care needs (CSHCN) are served through the Bureau for Children with Medical Handicaps (BCMh) through a diagnostic and/or treatment program. The Infant Hearing Program has an ongoing relationship with BCMh. Children who require diagnostic, audiological evaluation following the newborn hearing screening and/or those who are diagnosed with deafness or hearing loss may be eligible for assistance under the BCMh program. BCMh covers many of the diagnostic procedures for evaluating infants and children. Treatment services may include fitting of amplification, cochlear implants, and/or other devices. BEIS provided funding to the Bureau of Child and Family Health Services to expand and enhance hearing clinics across the state in order to increase access.

The Ohio Department of Health has devoted significant funds and considerable effort into developing functional data systems for its programs. The Integrated Perinatal Health Information System (IPHIS), implemented in January 2006 by the Vital Statistics Division of ODH, contains information for birth certificates, universal newborn hearing screening results, perinatal hepatitis B, perinatal HIV, perinatal infections, and paternity affidavits. Vital Statistics

is the gatekeeper for major IPHIS functions. Hearing screening results and other data captured in IPHIS is currently being electronically extracted and imported into the HI\*TRACK database. Early Track, the birth to three early intervention data collection system, will continue to have data on infants and toddlers diagnosed with hearing loss/deafness, i.e. children who are receiving ongoing RIHP habilitative services.

Externally, ODH has collaborated with relevant agencies for public awareness and education regarding early hearing detection and intervention. Some of these groups include the Ohio Chapter of the American Academy of Pediatrics, the Ohio Department of Education, the Ohio Center for Deaf-Blind Education, the Ad Hoc Committee for Hearing Screening in the Schools, Deaf Initiatives, the Center for Outreach Services at the Ohio School for the Deaf, the Ohio Association for the Deaf, the Ohio Board of Speech Language Pathology and Audiology, the Cincinnati Children's Hearing Aid Trust, the Region 4 Genetics Collaborative (EHDI Follow-up Work Group), and the Northeast Ohio Consortium for Children's Cochlear Implants. The relationship with the Ohio School for the Deaf has been longstanding with an Infant Hearing Program consultant serving on the Outreach Services Advisory Council.

## **6) Data Requirements**

All birthing facilities are required to report screening results for infants through IPHIS. ODH currently is able to report on the number of UNHS results forms received from hospitals, which include the number of infants the hospitals reported that did not pass.

The RIHPs report to ODH the number of infants who receive diagnostic services by three months of age and the number enrolled in early intervention by six months of age through information they obtain from audiologists and families. Beginning in July 2009 the information is entered into HI\*Track and ODH will begin generating HI\*TRACK reports to monitor

enrollment. Hi\*Track, once the program is fully transitioned, will be used to generate state and federal reports.

The RIHPs are charged with linking families for support, but often must accomplish this through informal measures, i.e. sharing contact information between families with their permission; rather than through organized group activities. Family-to-family support groups and/or meetings to foster family support are included in activity reports submitted by the RIHPs via midyear and end of year reporting tables.

## **7) Activities planned to meet program goals.**

### **Goal I. Assure that all infants receive hearing screenings by one month of age**

Infant Hearing Program Staff will continue to monitor compliance with UNHS requirements and begin monitoring hospital referral rates utilizing the IPHIS individual Hospital Reports for each facility in conjunction with HI\*TRACK hospital reports. Technical assistance will be initiated if referral rates increase, complete screening results are not documented, or if there are other issues related to compliance with the legislative mandate. Staff will continue to utilize a standardized monitoring tool that covers both the UNHS process and quality assurance components at the hospital level. Staff will continue to emphasize steps to reduce loss to follow-up through communication in newsletters and targeted correspondence.

ODH staff will continue to promote the use of training materials provided to UNHS hospitals staff. The UNHS materials (printed items, videos/DVD's, CD's) are comprehensive. The *UNHS Training Materials 2007* covers reasons for a non-pass hearing screening result, emphasizes the need for further testing, and addresses how to convey information to parents in a culturally competent manner. The material stresses the importance of hospitals fostering parental trust and understanding of the UNHS process, emphasizes the importance of emotional

support to parents of infants who do not pass UNHS; and, the importance of next steps for timely follow-up evaluations.

Hospital quality assurance and internal consistency will continue to be emphasized. With the updates to HI\*TRACK, hospitals will have access to data reports for internal monitoring of their UNHS data. HRSA supplemental funding will be utilized to purchase or develop a series of web-based training modules for hospital personnel.

**Goal II. Assure that any infant not passing UNHS receives a diagnostic audiologic evaluation by three months of age.**

ODH will continue to monitor IPHIS data imported into HI\*TRACK and ensure that RIHPs track and provide follow-up on all infants who do not pass UNHS. ODH has been working with the NCHAM Help Desk to provide RIHPs with new referral lists so they can generate them on a daily basis, if desired, giving them immediate access to the non-pass results for their individual regions. Due to the protocol used by IHPIS there may be a delay of several days before complete screening data is updated in IPHIS. ODH is rethinking the need for a separate referral process at this time but evaluation is still underway. ODH staff will continue to concentrate on monitoring RIHP outreach, providing technical assistance and assessing need for and ways to improve the loss to follow-up based upon “real time” documentation.

ODH staff will continue to update and maintain a current Pediatric Audiology Services Directory. Staff will continue to reach out to audiologic resources, provide education on UNHS recommendations, and identify barriers and gaps throughout Ohio and explore ways to increase accessibility to services. Plans include additional outreach to pediatric audiologists.

**Goal III: Assure that all infants with confirmed hearing loss begin early intervention and habilitative services by six months of age.**

ODH staff will begin relying on RIHPs to enter data from the UNHS Follow-up Hearing Evaluation Reporting Form into HI\*TRACK. ODH will monitor reporting and referrals as documented by RIHPs. Staff will begin reviewing both HI\*TRACK and Part C Early Intervention data to assure that infants receiving RIHP services are also enrolled in Part C Early Intervention services.

ODH will continue to offer staff of the Regional Infant Hearing Programs training in the basic SKI\*HI curriculum and recertification as required in order to provide a family centered, culturally appropriate base for habilitative services.

**IV: Increase public and professional awareness of early hearing detection and intervention.**

ODH staff will continue to work with the Advisory Subcommittee to facilitate a regular exchange of information and recommendations that will build on the UNHS strengths and address weaknesses. ODH will seek to identify specific educational needs of physicians, families and audiologists; continue to produce and distribute resources, conduct outreach activities, and seek ways to work collaboratively with educational and professional entities to assure that the EHDI 1-3-6 goals are met.

It has been five years since the full implementation of UNHS in Ohio. Currently approximately ninety-three percent (93%) of babies born in Ohio hospitals and free-standing birthing centers have their hearing screened before discharge. The statewide referral rate, based on provisional data, is 2.7% and below the national target of four percent (4%). Continuing the monitoring and technical assistance processes currently in place will help to accomplish incrementally the objectives of screening all infants and maintaining a low rate of referral.

The RIHP's access to HI\*TRACK will assist in reducing delays in reaching out to families of children who do not pass their UNHS, but ensuring that infants who do not pass UNHS receive timely diagnostic audiologic evaluation remains challenging. Lack of pediatric providers in some geographic areas, travel time to providers, as well as long wait lists in more populated areas and poor access to insurance or transportation remain a concern.

Infants with confirmed hearing loss are referred to the Regional Infant Hearing Programs (RIHPs) for family-centered habilitative services in the infant's natural environment. The RIHPs are required to contact the family and to provide early intervention services through regularly scheduled visits. The Part C program funding will continue this unique and vital statewide EHDI program through June 2010. Thereafter, as mentioned previously, the program structure may change.

Communication is vital at every step in screening, diagnosing and treating hearing loss in infants. One barrier has been the lack of clear communication between the many involved parties (hospital screening personnel, parents, physicians, audiologists, ODH and RIHPs). Ohio's goal is to remove barriers to a seamless network of services, provide support for parents, and minimize delays in diagnosis and intervention. The ongoing efforts by ODH to reach out to the public, to work with parents as advocates and to provide information, expert recommendations and guidelines to audiologists, speech language pathologists and primary care providers, will increase knowledge and reduce barriers to the UNHS program for hearing impaired infants and toddlers in Ohio.