

## **IMPROVING VERMONT'S CHILDHOOD HEARING HEALTH SYSTEM**

### **BACKGROUND AND NEED**

Since mid-2003, every birth hospital in Vermont has committed to screening each in-born newborn for hearing loss and to reporting the results to the Vermont Department of Health (VDH) Newborn Screening unit, within Children with Special Health Needs (CSHN), Division of Maternal and Child Health (MCH). Newborns who are transferred before screening or who otherwise miss a screening (refusal; death; other) are also to be reported by the birth hospital. Out of state infants who are transferred into a VT hospital and are screened are also reported, as are home-birther babies who may have presented to their local hospital for hearing screening. For even more years, CSHN has organized and carried out the Hearing Outreach Program (HOP), the source of public health outpatient audiologic screening (including referral for diagnosis) for children birth to age four, including newborns who missed or who did not pass their newborn hearing screening. Vermont's HOP is a unique intermediary step between screening and diagnosis. It utilizes otoacoustic emissions (OAE) testing, performed by pediatric audiologists, at sites in or near every VT birth hospital. It reduces the number of infants not passing their hospital screenings and re-screenings by two-thirds (in 2005, 61 of 95 hospital-screened "refers" passed their outpatient HOP re-screening). EHDI staff are in daily contact with hospital screeners about data quality—misses, changed names, incompatible coding, unknown PCP, unreachable contact.

In June, 2008, Vermont completes its last year of EHDI cooperative agreement (UR3/CCU124789), funding from the Centers for Disease Control to support a tracking database which is fully integrated into the state's Child Health Profile (SPHINX—Shared

Public Health Information exchange). When completed (during FY 2009), newborn hearing screening results and tracking of follow-up steps will be entered electronically, de-duplicated with other entries (electronic birth certificates, immunizations, lead screening, and a planned series of other public health MCH programs) and available to primary care physicians. The project completes the transition from a paper reporting system to a fully electronic one. Since 2003, all birth hospitals fill out paper forms and mail them to the state EHDI program. They are entered into an Access database which is populated (electronically) by the newborn bloodspot screening demographics. Tracking milestones are entered as they occur and are accessible to the EHDI program staff by individual baby or by standardized query.

Legislation: Vermont does not have a law requiring hospitals to perform newborn screening. VDH has a statutory responsibility (18 VSA chapter 3 section 115 (b) (3)) for “early casefinding”, the rule on which VT newborn screening activities are based. Newborn screening regulations give VDH responsibility for assuring that newborns are screened for metabolic conditions and permit charging a fee to hospitals. This fee was increased in March, 2008, to help cover the costs more fully. Hospitals understand that the responsibility for *collecting* and mailing the bloodspot samples had been delegated to them. Bloodspot results, however, are reported to VDH by the laboratory with which the state contracts to process the samples (U Mass New England Newborn Screening Program, NENSP), whereas hearing screening results have to be reported to VDH by the screening hospital itself. Only one hospital has protested that reporting the results to VDH was a HIPAA violation. That issue was resolved by reference to a more recent bill (Act 32 (S. 159) enacted July 1, 2003) directing VDH to create a “Birth Information

Network” (BIN). BIN includes congenital hearing loss as a reportable condition up to the age of 12 months. At this time, audiologists who make the diagnosis of hearing loss. out of state hospitals performing screening, and early intervention programs do not report routinely. EHDI staff have to obtain results actively.

Vermont, like most states, has been unable to bring *every* newborn who does not pass the initial screening to diagnosis and early intervention within the ideal timeframes of screen-by-one-month, diagnose-by-three-months, and intervene-by-six-months. In 2005, Vermont had 6,139 in-state births of whom 5,877 (95.7%) were screened. There were nearly 200 homebirths, most of whom were not screened, so that the percentage of non-screened *hospital births* is quite small. Only ninety-seven of the 5,877 did not pass their final in-hospital screen, and of the 97, two died (percentage “refer”: 95 of 5,877, or 1.6%). Fourteen of the 95 were lost-to-re-screening (14.7%), of whom 4 refused. 81 of 95 were re-screened as outpatients, most at HOP, a few at hospital or community audiology. 61 of the 81 passed the outpatient re-screening. 20 did not pass their re-screenings and were referred to diagnostic audiology. 16 of the 20 received diagnostic audiology, of whom 10 passed and 6 were diagnosed to have hearing loss. Four of the 20 (20%) did not have diagnostic testing and were lost to diagnosis. All who were diagnosed with hearing loss were referred to early intervention. Overall lost to follow-up rate was 18.9% (18 of 95), a figure which (as explained above) does not include the non-screened home births.

To address the lost-to-follow-up rates, in April, 2008, Vermont received new HRSA EHDI funding (HRSA 08-030, CFDA 93.251) for program improvements, including increased parent leadership, strengthened reporting agreements and protocols,

expanded diagnostic capacity statewide, and improved collaboration with early intervention programs. With HRSA EHDI funding, we will be hiring a parent program advisor through the statewide early intervention program to interview families to identify strengths and weaknesses of their child's journey from screening to early intervention. A Hospital Screeners group will identify improvements needed to improve screening practices and documentation. We will be staffed for increased direct communication with PCPs to assure timely and appropriate re-screening, diagnosis, and treatment. HOP outreach clinics will expand their AABR and ABR tools for monitoring high-risk babies and for unsedated ABR diagnosis statewide. Interstate agreements will allow for data-sharing across state borders.

We view the goals and activities proposed in this application as the ideal partnership with the new HRSA EHDI grant activities to bring system improvements to fruition. The HRSA EHDI goals are directed at assurance that screening and necessary follow-up diagnosis and intervention take place in a timely fashion and are of the highest quality; the HRSA EHDI activities are largely clinical in orientation. The goals of this proposed CDC project address the documentation and the accountability of the system. In essence, the HRSA EHDI grant addresses the *assurance of doing* the screening, the tracking, the follow-up, the diagnosis, the early intervention. This proposed CDC project will address *the accountability of the doing*.

There are three core goals of this proposed project: (1) Improved data quality, comprehensiveness and timeliness through improved methods of collecting and reporting on the improved clinical activities; (2) improved accessibility to and utilization of the data for the purposes of overall EHDI system improvements and for aggregate reporting

for national EHDI surveillance/evaluation; and, (3) maximum feasible integration of data with other elements of state Child Health Profile.

## **WORKPLAN**

We propose staffing and managing the project activities as described in more detail in the STAFFING AND MANAGEMENT section, below. Briefly, we will hire a public health statistician to be the Project Manager who will be a full-time state employee. Part-time support will also be provided to a project secretary, project administrative assistant, and the project audiologist who also oversees the state's EHDI effort. Additional services and consultation to the project will be obtained through funding the hours of assistance from the VDH IT unit, for the Helpdesk, and from UVM VCHIP data specialist to help with quality improvement activities. The project will be part of the Newborn Screening unit, within the Children with Special Health Needs Unit, Division of Maternal and Child Health, Vermont Department of Health.

### **Goal 1: To improve the quality, completeness, and timeliness of the collection of data and reports of EHDI clinical activities**

As described in BACKGROUND, the Child Health Profile—the VDH SPHINX database—contains the Childhood Hearing Health System (CHHS), as an integral--not just linked--unit. There is a data field, for each and every demographic, clinical, service, clinical tracking, outcomes, and text, information item necessary for clinical patient tracking and management as well as for aggregate reports. The database is already constructed; the final releases and implementation phases will take place in the first half of FY 09. The goals, therefore, are *not* to build storage places, but to assure, first (through the HRSA EHDI grant) that all babies are receiving what they need—when they

need it, and, through this proposed project, that all services and needs are recorded accurately, completely, and timely, and are utilized for system improvements.

For each baby, the CHHS data will merge with pre-existing entries from the VT EBRS (Electronic Birth Registration System--birth certificates), bloodspot screening, and occasionally, neonatal immunizations. It is also possible that the neonatal hearing screening report itself might be the first entry for a baby. Bloodspot screens will be reported as they now are (from the New England Newborn Screening Program Lab at UMASS) and may include unregistered home births. For babies born at in-state hospitals, we are able to run queries to identify babies who have not had a hearing screen or babies whose hearing screen has not been reported. Follow-up of misses require personal staff effort, sometimes extensive, to confirm or correct. The greatest gap is *not* the number of known misses (because hospitals report misses), but the number of *non-reports* (most of which have been screened). Similarly, babies whose screen has (or has not) occurred out-of-state, appear as babies with non-entries in the screening field. Each non-report requires significant staff effort to research and retrieve and results in deficits in timeliness and completeness. Inaccuracies (some unavoidable, such as when babies' or parents' names change) also require staff time and affect data quality. EHDI staff are in daily contact with hospital screeners about individual data quality issues—misses, changed names, incompatible coding (e.g., low birth weight/NICU admission with no plan for follow-up of risk).

Goal 1—Objective 1: To reduce the number of non-reports of neonatal screening of hospital-born babies by 90% by the end of the project.

We will begin with analyzing current patterns in non-reporting, and target remediation to the hospitals with the highest rates. We will also continue our current practice of contacting the hospital screener whenever a baby is not reported. We will measure the reduction in non-reports—while also noting the corresponding decrease in staff time required to call hospital nurseries. *Who: Project Manager, secretary/admin support.*

Goal 1—Objective 2: To reduce the number of non-reports of neonatal screening for Vermont babies transferred out of state by 90% by the end of the project.

Completion of interstate agreements with New Hampshire and Massachusetts (under the HRSA EHDI grant) will pave the way for establishing reporting expectations with out of state hospitals. New York will remain difficult, until NY requires reporting with infant identification. We will convene a workgroup of parent advisors, representatives from NH, MA, and NY EHDI programs, and representatives from Dartmouth Hitchcock Medical Center (NH) and Albany Medical Center (NY), to devise the most efficient, streamlined method of reporting screenings and misses, under the new agreements. Questions may include whether reports will be transmitted by the states' EHDI programs or by the hospitals; whether reports will be in response to requests (with VT EHDI sending prompts) or proactive. *Who: Workgroup; project staff.*

Goal 1—Objective 3: To reduce the number of reported missed babies who have no documentation of outpatient screening or re-screening, by 90% by end of project.

Most babies who miss their inpatient screens or who are “refers” are referred to HOP for next steps. Some hospitals, however, bring babies back to hospital audiology or to programs for recently discharged babies. Methods need to be developed to capture

these alternative screening/follow-up events more consistently and efficiently. We will convene a workgroup of these sources and parents who have participated in these, to devise proactive reporting mechanisms, test, revise, and implement in the second year.

*Who: Workgroup; project staff.*

Goal 1—Objective 4: To reduce the interval between diagnostic testing and reporting to no more than 2 weeks, for 90% of babies, by end of project.

The HRSA EHDI grant addresses increasing the access to timely and definitive diagnosis of hearing loss in infants, by expanding HOP and by adding new community-based centers, and by PCP and parent information to stress the urgency of diagnosis and medical investigation. When HOP is able to perform diagnostic testing, the results will be entered directly into the integrated database. If HOP is involved in re-screening and referral to a diagnostic center, we will—if families wish--assist families in making appointments and obtaining follow-up contact permission. However, when babies go to other providers for diagnosis, some of whom are out of state, obtaining final reports is often very delayed and labor intensive. We will meet with representatives of diagnostic centers, to promote BIN as sufficient requirement for reporting of diagnostic results, to inform of interstate data agreements when they are completed, and to devise the most efficient reporting format. *Who: Project staff.*

Goal 1—Objective 5: To increase to 100% the percentage of babies identified with hearing loss who are entered into active early intervention within 2 months of diagnosis.

In Vermont, the diagnosing audiologist is the principal referral source of a baby with newly-diagnosed hearing loss to the early intervention system. There are two components of that system, the comprehensive early intervention system, Family, Infant



and Toddler Program (FITP) and the specific component for babies with hearing which, in turns, contacts FITP. Referral, IEP signature, and initiation of appropriate services are all separate events, and not always swiftly accomplished. As elsewhere, the HRSA EHDI grant will address a formal agreement between VT PIP and EHDI concerning reporting. As above, the database is ready to receive data—*when it comes in*. The challenge, as with each objective in Goal 1 is to find a simple and reliable method for the events to be reported, without unduly burdening the reporters (EI, in this case) or requiring EHDI to pursue the information child by child. We will develop a consistent and effective reporting mechanism for practical implementation of that agreement. *Who: VT PIP director; HRSA EHDI Parent Advisor; project staff.*

Goal 1—Objective 6: To expand sources of follow-up information and confirmation through collaboration with Medicaid claims data and others, by end of year two.

VDH collaborates with Medicaid on multiple data projects involving claims data. The Project Manager will pursue specific child-find strategies, compatible with the Birth Information Network statute, to identify children diagnosed with hearing loss and to track interventions. *Who: Project Manager.*

Goal 1—Objective 7: To provide ongoing technical support for data reporters, as a Helpdesk function, throughout the project.

We will model the Helpdesk function on the existing Helpdesk now involved in the implementation of the SPHINX Immunization Registry element, through supporting the IT staff time necessary. *Who: Project Manager in collaboration with VDH IT staff.*

**Goal 2: To improve accessibility to and utilization of data as a tool for statewide EHDH system quality improvement and reporting for national surveillance and EHDH evaluation**

Just as the HRSA EHDH grant supports multi-dimensional strategies to assure that babies receive quality follow-up, and Goal 1 addresses quality, comprehensiveness, and timeliness of reporting encounters and results, Goal 2 aims to make the database a living, thriving system partner, a tool for analyzing needs and trends on multiple local and state levels for Vermont system improvement, and a tool for gathering aggregate reports to speak for Vermont's place in national EHDH program evaluation.

Goal 2—Objective 1: To hire Project Manager/statistician and to contract with VCHIP for the VCHIP Data Specialist by end of first quarter, year one.

The Project Manager is the key position for the implementation of this proposed project. The VCHIP consultant will add expertise and experience in quality improvement activities (see COLLABORATION section, below).

Goal 2—Objective 2: To complete transition from current Access databases to fully functional integrated database by third quarter, year one.

Although completion of the database is a product of the current, sunseting CDC cooperative agreement, the new project manager/statistician will participate in every aspect of the final phase, with an eye to how access to the information will benefit the patient level, program/system level, and contribute to national understanding. Meeting regularly with the EHDH team, the Project Manager will begin to draw together needs assessment and strategies that can be informed directly by the CHHS. *Who: Project*

*Manager, in collaboration with current EHDI project staff, including VDH IT staff assigned to completing this implementation.*

Goal 2—Objective 3: To develop local and statewide system status reports utilize EHDI data for statewide system improvements, by mid year two.

We will develop routine quality improvement reports that guide remediation steps, such as:

- Monthly reports of screening and completeness by facility
- Monthly statewide diagnosis and intervention reports
- Semi-annual VT system status reports including false positive rates, lag-to-next step rates, screening rates by maternal and other demographics.

The project manager/statistician will lead a workgroup of EHDI staff, Advisory Group members, parents (under the Parent Advisor) and other partners, including VCHIP, to suggest and select key system indicators for these overall system reports.

*Who: Project Manager and workgroup; VCHIP consultant; HRSA EHDI Parent Advisor.*

Goal 2—Objective 4: System remediation based on detailed status reports (Objective 3) will include annual outreach (site visits) and annual skills workshops, beginning year 2.

Annual site visits to each hospital and an annual skills (including reporting skills) workshop will complement—and reduce-- the child/report-specific contacts now necessary to assure quality data. *Who: Project Manager, Project Audiologist; HRSA EHDI Screeners Group*

Goal 2—Objective 4: To respond comprehensively to national reporting requirements annually.

The project manager/statistician (PM) will participate in all national activities requiring state representation. Anticipating the parameters of national reports, the project manager will develop queries to meet the demands. For example, maternal demographics, including maternal education, are available from the EBRS and, with integration through SPHINX, correlating reports with hearing screening will be routine. *Who: Project Manager.*

Goal 2—Objective 5: Newborn screening information will contribute to the larger MCH needs assessment process for Vermont’s annual report and application to Title V.

The PM will immediately begin to participate in MCH planning forums, particularly those which prepare for the title V needs assessment. These are existing workgroups which meet regularly. *Who: Project Manager.*

**Goal 3: To assure maximum feasible integration of data with other elements of state Child Health Profile--SPHINX.**

Goal 3—Objective 1: The project manager will immediately join appropriate department level committees on data integration and use them as a forum in which to discuss fruitful uses of the data.

The strength of Vermont’s current EHDI data project lies in its integration with the SHPINX Child Health Profile system. The EHDI database was designed as fully part of SPHINX, not as a separate database that needed to be linked after the fact. The sequence of adding new elements to SPHINX is managed at the department level. There is a SPHINX integration committee in which EHDI is a participant. *Who: Project Manager*

Goal 3—Objective 2: The extent to which the metabolic (bloodspot) screening program should be integrated into SPHINX will be decided by end of year one.

At issue is whether the integration should include a summary “normal” “needs follow-up” “critical abnormality” available to the PCP, or more specific information. By the end of year one, a workgroup comprised of PCP representatives, the AAP, and staff will make a determination. *Who: Workgroup and staff.*

Goal 3—Objective 3: The extent to which community audiologists should have viewing access to the EHDI status of their patients will be determined by end of year two.

The project audiologist will convene a workgroup, comprised of parents and audiologists to make this determination. *Who: Workgroup and Project Audiologist.*

Goal 3—Objective 4: A proposal for additional data fields, beyond those included in the final current product, will be presented to and approved by the VDH IT priorities committee by the end of the second year.

While the final version of CHHS meets all parameters for current EHDI data needs, SPHINX holds great promise as a larger tool for patient care and public health systems development. Expansion of data fields to include children identified with hearing loss at all ages, as well as children with chronic conditions receiving care through CSHN programs, is a logical step and is compatible with the state’s Blueprint for Health and its focus on chronic conditions. *Who: The MCH director, the CSHN director and medical director, the project manager, parents, and other stakeholders, will convene in the second year to develop a proposal for this expansion.*

Goal 3—Objective 5: Resources for SPHINX expansion will be sought and secured during the final year of this project.

The expansion will be targeted to begin at the end of this project, utilizing funding which project staff will secure through grant applications and/or collaboration with larger AHS data projects. *Who: project staff.*

## **COLLABORATIVE EFFORTS**

- ***Collaboration for EHDI HRSA Grant and CDC Cooperative Agreement***

The applicant organization collaboration within the Health Department: The state's EHDI program resides within the Vermont's Children with Special Health Needs (CSHN) program, of the Division of Maternal and Child Health, of the Vermont Department of Health, within the Agency of Human Services. It is the mission of CSHN to promote the well being of Vermont children with developmental and special health care needs. Our mission is consistent with the Healthy People 2010 goals of assuring that "children with special health care needs have access to a medical home," and that all "states...have service systems for children with special health care needs." CSHN provides family-centered, community-based, coordinated services for Vermont children with special health needs and their families through direct services (clinics), care coordination, financial assistance, family support, and system-building activities. The newborn screening program within CSHN is responsible for the metabolic and universal newborn hearing screening programs. The program provides oversight to ensure all newborns are screened, and that follow-up care is provided to all newborns that have had positive screens. CSHN pediatric nurses and medical social workers are based in regional offices. Staff are involved in care planning and coordination, including transitions from one care setting to another. Families are referred to CSHN from

Medicaid's High-Tech program when it is first determined that the child will need intensive, home-based medical care.

- *The current and proposed project activities will continue within CSHN.*

Collaboration with Bloodspot screening: The newborn screening program, for many years being only a bloodspot screening program, is now the organizational unit within CSHN overseeing both hearing and bloodspot screening; therefore, a single administrative structure interacts with hospitals and nurseries around these efforts. Both programs work closely with their over-the-border counterparts (in NH, NY, and MA) for babies born in one state but living in the other. Comprehensive intervention and support for VT babies identified through both screening programs is provided through CSHN. The Newborn Screening Chief is a public health nurse who reports to the CSHN director, who, in turn, reports to the MCH director.

- *Bloodspot screening will continue to be co-located and co-managed with the EHDI program. Bloodspot results will be integrated into SPHINX in a format useful for PCPs.*

Collaboration with VT Chapter of the American Academy of Pediatrics: VDH, including CSHN, collaborates closely with primary care providers through several projects and relationships with the VT Chapter of the AAP, and the VT AAFP. Monthly meetings of the AAP executive committee and AAFP president, with the VDH MCH director, are held to address child health care and systems issues. The EHDI program has participated in AAP continuing education efforts, and has sought advice from AAP on EHDI protocol and program needs. With respect to medical homes, CSHN partnered with the AAP through a HRSA/MCHB-funded Medical Home grant, and also participated with AAP in

the Medical Home Learning Collaborative II of NICHQ. The CSHN medical director and Child Development Clinic director, pediatrician Carol Hassler, MD, who oversees clinical aspects of newborn screening programs is also the AAP EHDI Chapter Champion for Vermont. Her supervisor, Wendy Davis, MD, is the MCH director and past president of VT AAP. The current AAP chapter president, Kimberly Aakre, MD, is a developmental pediatrician who works half-time in the CSHN Child Development Clinic.

- *The CSHN medical director will continue as the AAP EHDI Chapter Champion. AAP has a significant advisory role with the clinical activities of the new HRSA grant, on which the data improvement activities are based. PCP (Medical Home) activities are supported through the HRSA EHDI grant. This proposed project will improve the completeness, timeliness, and value of the data to PCPs who will have direct access through the SPHINX Child Health Profile.*

Collaboration with University of Vermont (UVM) Department of Pediatrics, Vermont Child Health Improvement Program (VCHIP): For many years, VDH has contracted with VCHIP to provide support to quality improvement efforts directed at primary care and health screening. More recently, the collaboration has expanded to include improvement of specialty services to children with certain chronic conditions, with a particular focus on patient management databases both to improve care to individual children and to chart clinic-wide improvements in patient outcomes. The MCH director oversees the contractual collaboration with VCHIP and directs its priority-setting. Other CSHN collaborations with UVM include: contracts with departments to provide direct and consultative services; faculty appointments for MCH and CSHN physician staff.



- *We will contract with VCHIP for consultation by the VCHIP Data Specialist, who will participate as an advisor to the uses of the data for system improvements (Goal 2 and 3), as well as overseeing the Evaluation component.*

Collaboration with Early Intervention: Until the major 2004 reorganization of the (umbrella) VT Agency of Human Services, CSHN was, for twelve years, also the administrative home of the state's Part C program. CSHN social workers continue to staff each of the 12 regional Part C programs, and the CSHN business office continues to process the payer of last resort bills so that families experience a seamless fiscal system (whether their child receives care through Part C, CSHN, or both). Our collaboration has continued, even with Part C transferred to a newly created Department for Children and Families. Our MCH Director co-leads the a new AHS Children's Integrated Services initiative in which the Part C program, the Healthy Babies Kids and Families Program (public health nursing support for at risk families), early childhood mental health services, services for children with special health or developmental needs, and the primary care medical home, will work towards improved access and service integration. The specific early intervention team for children with hearing loss, VT Parent Information Program of the VT Center for the Deaf and Hard of Hearing, continues to partner with CSHN/EHDI in direct services to young children and in creating continuing education programs for staff. Under the new HRSA grant, a Parent Advisor will be hired for the EHDI program in partnership with VtPIP, a major expansion of our collaboration both with parents and with VtPIP. CSHN funds assistive listening devices for children with hearing loss to the extent they are not covered by insurance (and most are not).

- *The EHDI Parent Advisor will be hired through the early intervention program, as described above. The HRSA grant addresses developing agreements for data sharing. This CDC project will address the practical processes of data sharing, reporting of referrals and their EI status.*

Collaboration with audiologists: The EHDI Program Audiologist organizes semiannual inservices and networking events for all audiologists serving Vermont children or expressing interest. These meetings build extraordinary goodwill between the state EHDI program and audiologists, most of whom are in private practice, and on whom the system of care for children with hearing loss depends. The resulting relationships also improve the receptivity for suggested best practice improvements and protocols. Audiologists self-identify their pediatric skills and interests, for inclusion in the Resource Directory for Children with Hearing Loss, published every few years by the Advisory Council which has helped to guide CSHN for many years.

- *Audiologists serving VT children are essential collaborators for assuring that babies with hearing loss are diagnosed and amplified (where appropriate). The HRSA grant addresses the possibility of legal reporting requirements. This project will address the practical aspects of reporting, consistent protocols for doing so, methods to improve consistent, active reporting, rather than staff labors for tracking down results and follow-up.*

Collaboration with Vermont Medicaid: CSHN programs have a decades-long collaborative relationship with Vermont Medicaid (Office of Vermont Health Access) around several critical functions: health insurance coverage for children; special access for children with disabilities (TEFRA option); advocacy for specific coverage of services

medically necessary for children with special health needs; reimbursement to CSHN for services that CSHN programs provide to Medicaid eligible children; improving access to Medicaid data to help with systems planning. Because CSHN is also a payer for health care, there is a strong focus on collaborative policy-making. For example, CSHN was instrumental in achieving Medicaid coverage for digital and programmable hearing aids, without requiring “failure” of analog aids.

- *Medicaid will be a key collaborator, through claims data, under the permissive BIN statute. Claims data will allow confirmatory evidence that a Medicaid-covered baby has, indeed, been evaluated by audiology and ENT.*

Collaboration with parents: CSHN provides considerable annual grant support to Parent to Parent of Vermont and to Vermont Parent Information Center, to support their infrastructure and outreach/information/support to parents. In July, 2008, these two organizations are merging, to improve their synergy and efficiency. The CSHN medical director serves on their Transition committee.

- *Infrastructure support will continue. Through the HRSA grant, a parent advisor is being hired and parent feedback on the screening-through-intervention process will be gathered and improved parent materials will be developed.*

## **PROGRAM CAPACITY**

Vermont’s EHDI Program: CSHN developed and manages the comprehensive EHDI program with the initial support of a HRSA EHDI grant, a new HRSA grant (see above) and the sunseting cooperative agreement from the CDC. Since 2003, all 12 birth hospitals in VT now perform UNHS and report the results to the EHDI program, which assures follow-up. The CSHN program has, for many years, supported a Children’s

Hearing Advisory Council. Through some members of the council, the legislature established a study commission in 1999 to recommend whether the state should implement UNHS. The CSHN director chaired the commission, which recommended UNHS and immediately implemented the Hearing Outreach Program (HOP), an itinerant OAE screening clinic held at each birth hospital, to make screening available before UNHS could be in full operation. The VT Association of Hospitals and Health Systems strongly supported the HOP effort, including seed funding. CSHN partners with Fletcher Allen Health Care Department of Community Outreach (FAHC is the state's tertiary care hospital) for staffing of this clinic.

The EHDI program currently includes a fulltime project audiologist who oversees all aspects of the newborn hearing screening effort and tracking, and who also oversees the Hearing Outreach Program follow-up services. There is a fulltime secretary to support HOP and a part-time secretary to support the database development of the current CDC cooperative agreement. Staff have been assigned from VDH Information Technology to carry out development, use cases, releases, revisions, and implementation of the database. Consultation is provided as needed from the BIN coordinator and MCH [what is Peggy's title?]. The Newborn Screening Chief, the CSHN director and the CSHN medical director (who is the HRSA EHDI PI), and the MCH director provide guidance and accountability. In addition, HOP direct services to babies needing re-screening, are provided by two pediatric audiologists (one full-time, one part-time) through a contract with FAHC.

As described above, HOP provides statewide initial (if missed in hospital) and re-screening, for referral to diagnostic services. For babies seen at HOP, all encounter

information will be recorded directly into SPHINX and integrated with EHDI and Child Health Profile data. Maintaining the quality, capacity and accessibility of HOP is the keystone to Vermont's public health assurance for newborn screening. HOP audiologists provide direct, face to face care for babies and their families, providing expert interpretation of results and next steps for diagnosis, explaining the importance of early diagnosis and intervention, and supporting families in accessing diagnostic audiology. HOP also communicates results and recommendations to primary care physicians and provides contact information about diagnostic centers. The reporting gaps are for babies whose follow-up does not loop through HOP. This is an area for effort with this proposed project.

Diagnostic facilities for infants under the age of 6 months continue to be quite restricted. Vermont's only in-state tertiary care center, which is also the only facility in VT which provides infant diagnostic ABR, does not perform sleep-deprivation and uses only sedation/general anesthesia. Three other tertiary care centers, each over the border in NH, NY, and MA, do attempt sleep-deprived ABRs. Referral of newborns to office audiology, utilizing sound-field technology, has resulted in multiple visits over months, without timely conclusion, when the monitoring and treatment of intervening middle ear disease has obscured the urgency of a diagnosis of possible underlying sensorineural hearing loss. Our program's Hearing advisory council identified inconsistent medical diagnosis to complement audiologic diagnosis as a concern as well. The new HRSA EHDI grant supports new capacity for HOP to provide diagnosis (using new non-sedated ABR technology) and face-to-face interpretations and referral to intervention and treatment. The grant also addresses interstate agreements which would permit cross-

border reporting from out of state diagnostic centers. The focus of this proposed project is the practical aspects of reporting.

See also COLLABORATION, above, for description of system elements and current and proposed collaborative activities.

As described in BACKGROUND, above, two sequential CDC collaborative agreements have supported, first, the development and successful, stable implementation of a paper-based screening reporting system, then an interim Access database populated by newborn bloodspot screening demographics into which hearing screening and tracking information is entered, and the final product, full integration of EHDI data into the state's comprehensive Child Health Profile/SPHINX. There are two hearing programs included in the SPHINX project: the EHDI program which applies to all children born in the state, and the Hearing Outreach Program, which includes those children recommended for follow-up screening. Both of these programs are supported with Microsoft Access® applications that are being replaced by this new endeavor.

## **STAFFING AND MANAGEMENT PLAN**

This application proposes to support:

- A full-time Project Manager who is a public health statistician, who will be a state employee affiliated with the Division of Health Surveillance, VT Department of Health. The position will be oversee all aspects of this project, and will be the liaison with other MCH data functions of the Health Department and the Agency of Human Services, and with the VCHIP consultant. In addition, the manager will be position to contribute to the governor's Blueprint for Health Initiative, a focus on chronic disease management and prevention which is a highlight of the

state's health care improvement goals. This position will also be the liaison to the VDH IT unit which has created and maintains SPHINX.

- The EHDI Project Audiologist position to the extent it is not supported through the new HRSA EHDI grant. This position is held by Stacy Jordan, a pediatric audiologist who has been overseeing the current EHDI activities and HOP for three years, and who served as a HOP audiologist for 4 years previously. In addition, she implemented the FAHC universal newborn hearing screening program, serving over 2,000 annual births. A contract with FAHC will support this fulltime position in the department of Community Health Improvement, but which is co-located in VDH/MCH/CSHN. This position coordinates the management of the HRSA EHDI project and this proposed project, in collaboration with the Newborn Screening Chief.
- A part-time administrative assistant, hired through a contract with FAHC.
- Consultation from the VCHIP Data Specialist, to advise the project on utilization of the data for quality assurance (Goal 2) and development of an expansion proposal (Goal 3). The consultation will also include overseeing the design of the project evaluation component.
- Partial, as needed, funding to VDH IT to support a Helpdesk function under the management of SPHINX, modeled on the SPHINX Immunization Helpdesk.
- Partial funding for a project secretary, a fulltime state employee who also supports HOP data and is partially supported by HOP revenues.
- Significant in-state staff travel to birth hospitals, and some out of state travel to collaborating hospitals

- Travel and registration costs for two staff to attend the required annual EHDI national meetings.

In Addition, the HRSA EHDI grant supports

- Partial funding for the Project audiologist, for her participation in project activities, implementation of HOP maintenance and improvement activities, supervision of all HOP activities and personnel, technical assistance to screeners, PCPs, statewide audiologists.
- Parent Advisor, part-time, through a contract with Vermont Center for the Deaf and Hard of Hearing for parent advisor, to assist project in all activities, and to take lead in parent interviews and evaluation.
- Funding for a part-time clinician manager who will function as the manager of the specific HRSA EHDI activities and will join the management team of the proposed project.

Integration of these projects into the larger Newborn Screening Unit, Children with Special Health Needs, and Maternal and Child Health Division, will be overseen by:

- Cynthia Ingham, RN, Newborn Screening Chief
- Stephen Brooks, CSHN Director (supervising the Newborn Screening Chief)
- Carol Hassler, MD, CSHN Medical Director and clinical advisor to the EHDI projects (also AAP EHDI Chapter Champion)
- Wendy Davis, MD, MCH Director (supervising the CSHN Director and Medical Director)

**EVALUATION**



The EHDI team, comprising both HRSA EHDI and this proposed project staff, will meet weekly to develop strategies and review progress towards goals and objectives. EHDI meets quarterly with the Advisory Council, a parent-chaired, multidisciplinary group which advises CSHN on issues and needs for children with hearing loss, develops white papers, provides educational outreach to PCPs and families, publishes a resource directory, identifies emerging issues, advocates both within and without (e.g. with Medicaid) for policy development.

The VCHIP Data Specialist will contribute to the evaluation design for the project.

The sources of evaluation will include:

- The primary evaluation for Goal 1 objectives will be periodic runs of the completeness of the data. Logs of personal contacts necessary to pursue missing, inaccurate, or incompatible data will be kept and reviewed to assess impact on staff time.
- The primary evaluation for Goal 2 objectives will be the production of local and statewide reports to guide VT system improvements. Other utilizations of the data will also be developed.
- The primary evaluation for Goal 3 objectives will be the ultimate approval of the proposed expansion of the SPHINX to include children with many special health needs and the achievement of funding to enter into development.