Virginia Department of Health

CDC RFA DD08-908

Virginia Child Health Information Systems Integration Project II

Integrating and Linking the Virginia Early Hearing Detection and Improvement Program Tracking and Surveillance System with Other Child Health Systems

Cooperative Agreement for
Early Hearing Detection and Intervention (EHDI)
Tracking, Surveillance, and Integration
April 28, 2008

PROJECT ABSTRACT

Grant Program: Cooperative Agreement for Early Hearing Detection and Intervention (EHDI) Tracking, Surveillance, and Integration
Project Title: Virginia Child Health Information Systems Integration Project II
Organization: Virginia Department of Health (VDH), Division of Child and Adolescent Health, 109 Governor Street, Richmond, Virginia 23219
Project Director: Gayle Jones, MPH, CHES, Telephone 804-864-7713

Project Summary: VDH will use funds to support the Virginia Child Health Information Systems Integration Project II (VaCHISIP II). The purpose of the project is to (1) enhance the Virginia Early Hearing Detection and Intervention Program (VEHDIP) tracking and surveillance system to accurately identify, match, and collect unduplicated individual data; (2) enhance the capacity of VEHDIP to accurately report the status of every occurrent birth through the EHDI process for the purpose of evaluating the progress of the National EHDI goals; and (3) develop and enhance the capacity of VEHDIP to integrate its EHDI system with other Virginia screening, tracking, and surveillance programs that identify children with special health care needs.

Objectives. The objectives of the project are to (1) enhance methods to accurately identify, match, collect, and report standardized, unduplicated, individual identifiable data for every occurrent birth in Virginia through modification or enhancement of the VEHDIP secure, authenticated role-based, Web reporting system, Virginia Infant Screening and Infant Tracking System (VISITS II); (2) maintain authenticated role-based Web access reporting efficiency, quality of data, and security in VISITS II and incorporate same into any new VISITS modules or modifications; (3) improve reporting of VEHDIP standardized aggregated information extracted from unduplicated individual identifiable data on screening results; (4) improve reporting of VEHDIP standardized aggregated information extracted from unduplicated individual identifiable data on intervention service data; (5) increase data sharing, integration, and linkages with other child health information systems through collaboration with child health agencies; (6) develop and implement an analytic plan to address loss to follow-up rates; (7) develop and implement a mechanism to identify and collect standardized data on unduplicated individual infants and children with late onset or progressive hearing loss; (8) improve quality and efficiency of VEHDIP through implementation and evaluation of the recommendations of the VEHDIP Evaluation Report.

Methods. The following methods will be employed to achieve project objectives: (1) based on assessments of the desire and need for audiologists, birthing centers, and primary care providers to report EDHI data to VDH via VISITS, the system will be modified or new modules will be developed to allow such reporting; (2) through development and implementation of a learning collaborative consisting of primary care providers, birth hospitals, audiologists, and Part-C Early Intervention providers, local and state EHDIP processes will be analyzed and, based on findings, local processes and VEHDIP roles will be changed to improve effectiveness and efficiency; and (3) based on assessment and feasibility study findings, VISITS will be linked or integrated with other child health information systems, such as the Immunization Registry.

PROJECT NARRATIVE

PART 1. BACKGROUND AND NEED

Introduction

Funding Support. Using funds from this cooperative agreement, the Virginia Department of Health (VDH), Office of Family Health Services (OFHS), Division of Child and Adolescent Health (DCAH), Pediatric Screening and Genetics Services (PSGS), Virginia Early Hearing Detection and Intervention Program (VEHDIP), will establish the Virginia Child Health Information Systems Integration Project II (VaCHISIP II).

Purpose. The purpose of VaCHISIP II is to (1) enhance the VEHDIP tracking and surveillance system to accurately identify, match, and collect unduplicated individual data; (2) enhance the capacity of VEHDIP to accurately report the status of every occurrent birth through the Early Hearing Detection and Intervention (EHDI) process for the purpose of evaluating the progress of the National EHDI goals; and (3) develop and enhance the capacity of VEHDIP to integrate its EHDI system with other Virginia screening, tracking, and surveillance programs that identify children with special health care needs.

Background

Virginia Early Hearing Detection and Intervention Program. One of two programs in PSGS, VEHDIP's mission is to minimize or eliminate communication disorders resulting from hearing loss. The goal of VEHDIP is to identify or rule out congenital hearing loss in children before 3 months of age and to assure enrollment of those diagnosed with hearing loss in appropriate early intervention services before 6 months of age. Program services consist of providing information and referral to families; collaborating with birthing hospitals, primary care providers (PCPs), audiologists, and birthing centers; and educating the community about EHDI.

The VEHDIP Team consists of the following staff: (1) Program Manager (PM), (2) Surveillance and Evaluation Coordinator (SEC), Follow-up Coordinator (FC), Follow-up Specialist (FS), and Technical Support Staff (TSS). Pending award of a three-year HRSA MCHB Universal Newborn Hearing Screening and Intervention (UNHS) cooperative agreement, which begins September 1, 2008, a Quality Improvement Coordinator (QIC) will be added to the VEHDIP Team and the FS will continue on the team.

Newborn Hearing Screening Legislation. The Code of Virginia provides statutory authority for newborn hearing screening in §§ 32.1-64.1 (Virginia Hearing Impairment Identification and Monitoring System) and 32.1-64.2 (Confidentiality of records).

The Code requires VDH to establish and maintain the Virginia Hearing Impairment Identification and Monitoring System (VHIMS) to identify hearing loss at the earliest possible age among newborns and to provide early intervention for all infants identified with hearing impairment. Since July 1, 1999, all hospitals have been required to screen newborns prior to discharge and identify infants at risk for developing progressive or delayed-onset hearing loss The Code allows parental refusal based on religious objections. Infants screened whose results indicate the need for a diagnostic audiological examination must be offered one at a center approved by the Board of Health. Hospitals and audiologists are required to report findings to VDH.

Regulations entitled "Virginia Hearing Impairment Identification and Monitoring System" were promulgated by the Board of Health as required by the Code of Virginia and became effective July 1, 2002. Virginia Administrative Code 12 VAC 5-80 further defines the program and provides consistent guidelines for VHIMS implementation. The regulations cover

responsibilities of hospitals, VDH, and persons providing audiological services after discharge. Regulations undergo periodic reviews, which includes opportunities for public comment.

The Code of Virginia requires the state health commissioner to appoint and provide support services to an advisory committee to assist in the design, implementation, and revision of VHIMS. The VEHDIP Advisory Committee (VEHDIP Adv Cmt) must meet four times a year.

VEHDIP Role Related to Legislation. VHIMS has evolved into VEHDIP, which collects, maintains, and evaluates required hospital and audiological reports; approves and maintains a listing of diagnostic audiological assessment centers and providers skilled in giving pediatric services to infants; maintains written protocols for performing hearing screenings, re-screenings, and diagnostic evaluations; maintains written guidelines for reporting diagnostic audiological evaluation results to VDH using the VEHDIP Audiological Form and guidelines for hospitals to report screening results via the Virginia Infant Screening and Infant Tracking System (VISITS); provides training and technical assistance to hospitals required to screen and report results; makes follow-up information and services available to parents; provides required support services to the VEHDIP Adv Cmt; and participates in regulatory reviews.

Integrated Child Health Data System. PSGS has managed the development and implementation of a functional statewide integrated child health data system, VISITS I. This Web-based, integrated surveillance and data tracking system supports VEHDIP and also serves the Virginia Congenital Anomalies Reporting and Education System (VaCARES, Virginia's birth defects registry). VISITS I went live statewide in 2002. Originally developed by an outside vendor (Welligent LLC), VISITS I was brought in-house for ongoing hosting and security management by the VDH Office of Information Management (OIM).

Virginia Child Health Information Systems Integration Project I. With funding provided by a three-year CDC Cooperative Agreement for EHDI Tracking, Surveillance, and Integration, VaCHISIP I was established. By the end of the project (June 30, 2008), it is expected that the following goals will have been met: (1) produce and implement a redesigned Virginia Infant Screening and Infant Tracking System (VISITS II), (2) use VISITS II data for improved child and adolescent health clinical and programmatic decisions, and (3) integrate/link VISITS II with other child health information systems. VISITS II is targeted to be released June 30, 2008 and will be integrated with the new Virginia Electronic Birth Certificate (EBC). Hospital users will have a single point of entry for birth certificate, hearing screening, and birth defects reporting. VISITS II will continue to support tracking and data management functions for VEHDIP and VaCARES, and ultimately will provide automatic/semi-automatic referral functions to the Part C Early Intervention (EI) database, Infant and Toddler Online Tracking System Early Intervention (ITOTS), and the Care Connection for Children (CCC) database, Care Connection of Children System Users Network (CCC-SUN). CCC is a statewide network of Centers of Excellence for Children with Special Health Care Needs providing assistance in accessing specialty health care services and a medical home, care coordination, medical insurance benefits, resources, transition services, and family-to-family support.

Needs Assessment

Newborn Hearing Screening Rate Prior to 1 Month of Age, 2006. The percent of infants screened for hearing loss before 1 month of age has steadily increased over the last five years from 95.5% in 2002, to 99.3% in 2006 as reported to VDH. Virginia hospitals screen nearly all infants born in their facilities prior to hospital discharge (99.5%). Very few newborns are missed (0.4%), and almost no parents refuse the screening (less than 0.1%).

The Code of Virginia only mandates screening and reporting among infants born in Virginia hospitals. Data regarding infants born at home, freestanding birthing centers, military hospitals, and out of state hospitals are not mandated to screen and report to VDH. Two out of the three military hospitals in Virginia regularly report through VISITS I. The third military hospital reports aggregate data via e-mail. VEHDIP continues to work with non-mandated entities to increase reporting. Future system modifications to VISITS III will add role-based access for freestanding birth centers to facilitate reporting for infants born in that setting.

Audiologic Assessment and Diagnostic Evaluation, 2006. In 2006, 2,898 infants were referred for audiological assessment (2.8 % of those screened prior to hospital discharge). This cohort represents the biggest challenge to obtain complete and timely follow up. Of this group, 2,301 or 79.4% received a complete evaluation resulting in a definite diagnosis or rule out for hearing loss. In this group, 411 infants never had any audiological assessment results reported to VDH and 186 had some type of rescreening but no complete evaluation resulting in a diagnosis or rule out. A total of 597 infants, or one out of five who failed screening, were referred but complete assessment information was never received by VEHDIP.

Of all infants referred for hearing follow up, a significant percentage (19.9%) did not have an identified medical home according to VISITS data entry. VEHDIP has hired an additional staff person to assist with locating and accessing a medical home. Although nearly one out of five infants referred for additional hearing screening follow up did not have an identified medical home, CDC National Immunization Survey data (2006) indicates that nine out of ten infants in Virginia receive at least one of the CDC recommended vaccinations by 3 months of age. VaCHISIP II will explore partnering with the VDH, Office of Epidemiology, Division of Immunization (DOI) for access to immunization provider information and data matching

between cohorts. The DOI is currently implementing the Virginia Immunization Information System (VIIS) Registry as mandated by the Code of Virginia in 2005. VIIS is a secure web-based, CDC-sanctioned immunization registry using the Wisconsin Immunization Registry system as its base with some state modifications. At present, VIIS has 8.5 million records as its base for children born in Virginia since 1990. During the pilot phase, VIIS has partnered to build immunization records through data exchange with 32 private sector partners and 119 local health departments. VIIS plans to expand to 4,500 providers in the next three years. Since VIIS has the largest developed PCP reporting base for child health, VEHDIP will explore linking hearing screening data to enable PCP access and reporting. Confidentiality with regards to PCP access of hearing screening results, however, would require a change in the Code of Virginia.

Timely audiological assessment represents another area of need. Of the 2,228 infants who obtained a definite diagnosis, 88.6% received the diagnosis within 3 months of age. One issue impacting audiological assessment is the lack of audiologists who participate in the VDH approved list program. Only one-third (50) out of 150 audiologists have chosen to participate. Low participation is attributed to not using audiological equipment required to be on the VDH approved list and inadequate reimbursement fees. Acceptance of Medicaid patients is another barrier, particularly in the highly-populated Northern Virginia area which currently has only one audiologist accepting Medicaid. The Virginia Department of Medical Assistance Services (VDMAS), the Virginia Medicaid agency, recently raised audiologist reimbursement fees and issued revised Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Hearing and Audiology Program guidelines. Pending receipt of HRSA MCHB UNHS funding, the QIC will work to improve audiologists' participation and reporting. VEHDIP is currently surveying audiologists to ascertain ways to improve reporting and follow up. These results will help direct

future reporting efforts for audiologists, including potential electronic reporting via VISITS III.

The number of infants identified with hearing loss and reported to VDH has increased over the last five years from 92 in 2002 to 111 in 2006 (see Attachment 1. Figure 1). This number, however, falls short of the 300 cases expected annually. VEHDIP suspects that this is due to under reporting of unilateral and/or mild hearing losses, lack of accessibility to audiological facilities in rural areas, language barriers, and communication issues between PCPs and hospitals. Pending feasibility study results, VDH will develop a mechanism by which physicians and audiologists can electronically report data related to hearing screenings via VISITS III. This will enable VDH to improve surveillance of both follow up and suspected underreporting of infants diagnosed with hearing loss.

Early Intervention Services, 2006. The percent of infants reported to VDH, diagnosed with hearing loss, and enrolled in early intervention services before 6 months of age has increased over the last three years from 61.1% in 2004, to 70.5% in 2006 (see Attachment 1. Figure 2). In 2006, 86.5% of the 111 infants born that year and identified with hearing loss were enrolled in early intervention services. Of those infants, 78.4% began early intervention services before 6 months of age. VDH plans to collaborate with VDMAS to facilitate a data match between VEHDIP referred/lost to follow up clients and clients screened and diagnosed for hearing loss through EPSDT services. VDMAS has provided VDH with preliminary data for 80,000 hearing screening claims since 2003. This data will be used to discover how many lost to follow up clients are later identified in other mandated hearing screening settings.

Audiologist and Physician Reporting. Currently, under Virginia law, audiologists and physicians are required to report screening and diagnostic results to VEHDIP. The reports are

sent manually and data are entered into VISITS I by VEHDIP staff. The VISITS II redesign does not include electronic audiologist and physician reporting.

PART 2. WORK PLAN

Action Plan 1. VISITS III Enhancement

Goal 1: Produce and implement an enhanced VEHDIP tracking and surveillance system to accurately identify, match, and collect unduplicated individual identifiable data through enhancement of VISITS.

G 1 OB 1: By the end of year 3, methods to accurately identify, match, collect, and report standardized, unduplicated, individual identifiable data for every occurrent birth in Virginia are enhanced through modification or enhancement of the VEHDIP secure, authenticated role-based, Web reporting system, VISITS II.

Year-1 Activities:

1. **VISITS II Evaluation:** The Project Director (PD) will evaluate the efficiencies gained by VISITS II modifications and identify added staff capacity that results from these efficiencies.
2. **VaCHISIP Work Group:** PD will convene monthly VaCHISIP Work Group meetings in which the project will be monitored from both a technical and business perspective.
3. **VISITS III Audiologist Reporting Module:** The Project Coordinator (PC) will establish an Audiologist Work Group, which will include certain VEHDIP staff and audiologists. The Work Group will assess the feasibility of developing a VISITS III Audiologist Reporting Module; the assessment will include review of the findings/recommendations of the VEHDIP Audiologist Survey that will be completed August 2008. If indicated, the Work Group will develop proposed Audiologist Reporting Module functions that will be eventually

incorporated into the VISITS III Requirements Document. The Work Group will then function as an Audiologist User Group.

- **Note:** The VISITS III Audiologist Reporting Module requirements would be completed in year 2, and the module would be completed in year 3.

4. **VISITS III Birthing Center Reporting Module:** PC will establish a Birthing Center Work Group, which will include certain VEHDIP staff and birthing center staff. The Work Group will assess the feasibility of developing a VISITS III Birthing Center Reporting Module. If indicated, the Work Group will develop proposed Birthing Center Reporting Module functions that will be eventually incorporated into the VISITS III Requirements Document.
   - **Note:** The VISITS III Birthing Center Reporting requirements would be completed in year 2, and the module would be completed in year 3.
5. **Physician View/Reporting Capability:** PC will assess the desire and need for PCPs' access to child-specific EHDI data. This access will be assessed for "view only" capacity (to inform PCPs of screening results, diagnosis, and referral status), as well as for "reporting" capacity (to enter screening results obtained in the office setting). If it is found helpful to pursue electronic access and reporting for EHDI data by PCPs, further evaluation will be conducted as to the best approach. This feasibility study would explore electronic view options using VISITS. Alternatively, VEHDIP will consider the feasibility of using VIIS as a means of documenting and viewing screening results and diagnoses.

G 1 OB 2: By the end of year 3, authenticated role-based Web access reporting efficiency, quality of data, and security are maintained in VISITS II and incorporated into any new VISITS modules or modifications.

Year-1 Activities:

1. **VISITS II:** In-house end users of VISITS II will monitor the newly redesigned system for defects, report defects to the VISITS II helpdesk for resolution, and request programming modifications to ensure efficiency, quality of data, and security.
   - **Note:** In year 2, based on results of VISITS II studies and plans for new modules or modifications, the following quality improvement computer technologies will be incorporated into the VISITS III Requirements Document: (1) quality assurance to prevent problems and enhance standardization (e.g., range checks, automated calculations and conversions, coded data, drop-down windows, and standard data collection variables); (2) quality control to detect, measure, and enhance effectiveness (e.g., logic edits, date-posting fields, transaction logs, queries and reports, and case de-duplication); and (3) security controls that include the requirements of all standards and best practices contained in all relevant agency information system documents.

Action Plan 2. Reporting Enhancement

Goal 2: Enhance the capacity of VEHDIP to accurately report the status of every occurrent birth throughout the EHDI process for the purpose of evaluating the progress of the National EHDI goals, also referred to as the "1-3-6" EHDI Plan, through implementation of a learning collaborative (LC).

Background Note: The LC will include three local sites comprised of PCP practices, birth hospitals where those PCPs attend deliveries, audiologists serving the site area, and local Part C EI service providers. The LC will test local processes and VEHDIP role changes for improving VEHDIP effectiveness and efficiency in meeting the "1-3-6" EHDI Plan.

G 2 OB 1: By the end of year 3, reporting of VEHDIP standardized aggregated information extracted from unduplicated individual identifiable data on screening results—including but not

limited to: child date of birth, infant gender, maternal demographics (age, race, ethnicity, and education level), date of screen, and results (e.g. pass/not pass)—is improved.

Year 1 Activities:

1. **Identify Target Areas:** SEC will identify geographic areas with noticeably low rates of screening, diagnosis, and referral in compliance with the "1-3-6" EHDI Plan.
2. **Recruitment:** PD will recruit a Follow-up Analyst (FA) to assist with providing staff support (technical assistance, training, process redesign, and meeting facilitation) to the LC. The FA and the QIC will work together through the LC to identify root causes for poor data reporting/compliance, develop local and statewide interventions to correct those root causes, and use short cycles of change to assess effectiveness of those interventions.
3. **Establish Collaborative:** FA and QIC will recruit participants for each site in the LC. Contracts or letters or commitment will be established with each participating entity.
4. **Kick Off LC:** FA and QIC will convene one full LC meeting, and one follow-up meeting at each site. The full LC meeting will provide an orientation to the learning collaborative process, establish ground rules and expectations, and begin the process of brainstorming barriers that participants experience in assuring follow up of abnormal initial screening results in newborns. Local site meetings will orient other staff in participants' work settings and drill further into the local work processes that are needed to support follow up of newborns who fail the initial hearing screen, such as tracking methods and outreach to families who miss consecutive appointments. They will incorporate, as appropriate, suggestions from nationally published research related to newborn hearing screening such as the National Initiative for Children's Healthcare Quality (NICHQ) Learning Collaborative findings and/or other published survey results (e.g. Moeller et. al. Primary Care Physicians'

Knowledge, Attitudes, and Practices Related to Newborn Hearing Screening. *Pediatrics* 2006; 118; 1357-1370).

5. **NICHQ Strategies:** FA, with assistance from QIC, will initiate development of testing processes within the LC aimed at improving the rate and reporting of follow-up screening on infants who fail their initial hearing screen. New processes may be specific to VEHDIP staff roles or targeted to local LC participant needs. They will include strategies, as appropriate, found to be effective in the NICHQ learning collaborative: (a) scripting the message given the parents when an infant does not pass the initial screening test; (b) getting a second point of contact for the family, e.g., a relative or friend; (c) verifying identity of the PCP or clinic before the parents leave the hospital; (d) making the next appointment for the family and explaining why is it important to keep the appointment before they leave the hospital; (e) making reminder calls before appointments that include the reasons why the appointment is important; and (f) making use of the fax-back to alert the PCP of screening results and the need to prompt follow up.
6. **Medical Home Support:** FA will develop systematic processes to assist families in identifying a medical home and refer families to needed resources, such as state-sponsored health insurance.
7. **Monitoring Screening and Rescreening:** The SEC will continue to monitor, analyze, and annually report on the status and progress of every occurent birth statewide through the screening and rescreening processes.

G 2 OB 2: By the end of year 3, reporting of VEHDIP standardized aggregated information extracted from unduplicated individual identifiable data on diagnostic results—including but not

limited to: ear specific diagnosis (type and severity of hearing loss, i.e. minimal and unilateral), maternal demographics, and date of diagnosis—is improved.

Year 1 Activities:

1. **Learning Collaborative:** As described above, FA and QIC will convene one full LC meeting, and one follow-up meeting at each site. The full LC meeting will begin the process of brainstorming barriers participants experience in assuring completed audiological diagnostic evaluation by 3 months of age. Local site meetings will drill further into local work processes needed to support timely referral to an audiologist for diagnostic evaluation.
2. **NICHQ Strategies:** The FA, with assistance from QIC, will initiate development of processes to test within the LC aimed at improving the rate and reporting of infants receiving evaluation/diagnosis by an audiologist by 3 months of age. The new processes may be specific to VEHDIP staff roles, or targeted to local LC participant needs; they will include such strategies, as appropriate, found to be effective in the NICHQ learning collaborative: (a) making two audiology appointments so that the infant who cannot be completely tested at the first appointment is already scheduled to return in a reasonable timeframe and (b) making use of the fax-back between specialists, including the audiologist and PCP.
3. **Audiological Evaluation Appointments:** The FA, with assistance from QIC and PD, will assess VEHDIP staff roles, and PD will modify roles as needed to assist families in scheduling an audiological evaluation by a VDH approved facility. This assessment will take into account the extent to which audiologists currently track children with hearing loss or at risk for hearing loss to determine how the VEHDIP can help audiologists improve follow up.

4. **Diagnostic Evaluation Partnerships:** PD will establish relationships with approved offices that will facilitate obtaining diagnostic evaluation appointment for children and families in a timely manner (preferably before 3 months of age).
5. **Follow Up to Diagnosis:** FA, with assistance from QIC and PD, will assess VEHDIP staff roles, and PD will modify roles as needed to ensure that children with a scheduled diagnostic evaluation are closely tracked until a diagnosis is received.
6. **Monitoring Audiologic and Medical Evaluation:** SEC will continue to monitor, analyze, and annually report on the status and progress of every occurent birth statewide through the audiologic and medical evaluation processes.

G 2 OB 3: By the end of year 3, reporting of VEHDIP standardized aggregated information extracted from unduplicated individual identifiable data on intervention service data—including but not limited to maternal demographics, data of referral to Part C EI or other early intervention services, and date of enrollment in services—is improved.

Year 1 Activities:

1. **Learning Collaborative:** As described above, FA and QIC will convene one full LC meeting, and one follow-up meeting at each site. The full LC meeting will begin the process of brainstorming barriers participants experience in successfully referring a diagnosed infant to Part C EI services by 6 months of age. Local site meetings will drill further into the local work processes that are needed to support timely referral to early intervention services.
2. **NICHQ Strategies:** The FA, with assistance from QIC, will initiate development of processes to test within the LC aimed at improving the rate and reporting of diagnosed infants receiving early intervention services by 6 months of age. The new processes may be specific to VEHDIP staff roles, or targeted to local LC participant needs. They will include

strategies, as appropriate, found to be effective in the NICHQ learning collaborative such as obtaining consent for release of information at first contact with early intervention so that information can be entered in the State database.

3. **Early Intervention Resources:** FA will work with Part C EI Coordinator and/or staff to identify appropriate early intervention resources serving the LC PCP practices and all localities in general.
4. **Outcome Information:** FA will work with Part C EI Coordinator and/or staff to explore effective ways to obtain outcome information, including children referred from VEHDIP to Part-C and CCC, from referral sources and parents.
5. **Monitoring Early Intervention Services:** SEC will continue to monitor, analyze, and annually report on the status and progress of every occurent birth statewide through the early intervention referral processes.

Action Plan 3. EHDI System Integration and Evaluation

Goal 3: Enhance the capacity of VEHDIP to integrate the EHDI system with other Virginia screening, tracking, and surveillance programs that identify children with special health needs.

G 3 OB 1: By the end of year 3, VEHDIP will increase data sharing, integration, and linkages with other child health information systems through collaboration with child health agencies.

Year-1 Activities:

1. **Medicaid EPSDT Database:** PC will work with VDMAS to obtain Medicaid EPSDT data related to hearing screening and diagnosis and explore feasibility of performing data match through OFHS Maternal and Child Health Epidemiologist (MCH EPI) and/or OIM Data Warehouse. This match will help identify underreported cases of hearing loss and complete VEHDIP case ascertainment/lost to follow up.

2. **Immunization Registry-VIIS:** PC, in collaboration with VDH DOI staff and MCH EPI, will determine the feasibility of linking or integrating VISITS III with VIIS, and based on feasibility findings, will initiate a plan for linking VISITS III and VIIS.

G 3 OB 2: By the end of year 3, an analytic plan to address loss to follow-up rates including but not limited to the following elements will be developed: differences between key variables such as birthing facility, false positive rates, demographic differences (racial ethnic sub populations, gender, maternal age and education) and seasonal variations or other timing differences or geographic locations (urban vs. rural).

Year-1 Activities:

1. **Data Extraction:** SEC will extract demographic data from VISITS II using newly developed extract function on all clients lost to follow up and those receiving recommended services outside of expected "1-3-6" timeframes. VEHDIP follow up staff and QIC will assist in variable selection.

2. **Data Analysis:** SEC will analyze extracted data and prepare a report of findings which profiles lost to follow up clients.

3. **Other Child Health Data Sources:** SEC, in conjunction with VEHDIP staff, will develop plan to examine data available from other child health data sources (e.g. VIIS) that may contain VEHDIP lost to follow up clients.

G 3 OB 3: By the end of year 3, a mechanism to identify and collect standardized data on unduplicated individual infants and children with late onset or progressive hearing loss will be developed.

Year-1 Activities:

1. **Hearing Loss Data Sources:** PC will identify child health information systems that include children with hearing loss.

2. **Plan to Match Data:** PC, in collaboration with representative of at least one child health information system that includes children with hearing loss, will develop data match plan to identify children with delayed hearing loss not in VISITS II for implementation in year 2.

G 3 OB 4: By the end of year 1, VEHDIP will develop an evaluation plan to assure implementation of VEHDIP Evaluation Report recommendations, to be completed June 2008, for improving quality and efficiency.

Year-1 Activities:

1. **Review Findings:** SEC will meet with VEHDIP Evaluation Report authors (MCH EPI and Council of State and Territorial Epidemiologists Fellow) and other VEHDIP staff to review findings and recommendations. Evaluation methodology is based on "Updated Guidelines for Evaluating Public Health Surveillance Systems" July 27, 2001, *MMWR* (RR13).
2. **Survey Comparison Analysis:** SEC will prepare a comparison analysis report of the completed parental, maternal, and audiological surveys.
3. **Present Findings:** SEC, with MCH EPI assistance, will present report findings and recommendations (VEHDIP Evaluation and comparison analysis) to the VEHDIP Adv Cmt.
4. **Choose Recommendations:** PD, with VEHDIP Adv Cmt input, will determine which VEHDIP Evaluation Report recommendations should be implemented given priority needs, including comparison analysis findings, available resources, best practices, and requirements.
5. **Implementation**: QIC, with VEHDIP Adv Cmt input, will develop a plan for implementation of appropriate VEHDIP Evaluation Report recommendations.

G 3 OB 5: By the end of year 2, VEHDIP will develop a Surveillance Methodology Evaluation Plan for implementation on a long-term basis.

Year-1 Activities:

1. **Assess Plans:** SEC, in collaboration with QIC and MCH EPI, will assess the efficacy of developing a combined VEHDIP-VaCARES Surveillance Methodology Evaluation Plan (SMEP) for implementation at periodic and regular intervals on a long-term basis.
2. **Coordinate Plans:** SEC, in collaboration with QIC and MCH EPI, will initiate development of a combined VEHDIP-VaCARES SMEP Plan based on assessment findings.

PART 3. COLLABORATIVE EFFORTS

State-Level Advisory Group. The VEHDIP Adv Cmt provides an existing mechanism for convening regular meetings of all EHDI stakeholders. This group will continue to meet face-to-face on a regular basis and will assist the VaCHISIP Work Group in identifying gaps and accomplishing certain activities. The VEHDIP Adv Cmt consists of representatives of stakeholder organizations and individual stakeholders, including health insurance industry, physicians (Virginia Chapter-American Academy of Pediatrics Chapter Champion, geneticist, otolaryngologist, neonatologist), nurses, audiologists, hearing aid dealers and fitters, teachers of the deaf and hard-of-hearing, parents of children who are deaf or hard-of-hearing, adults who are deaf or hard-of-hearing, hospital administrators, and personnel of appropriate state agencies. (See Attachment 2. Letters of Support.)

National Collaboration. A VaCHISIP II representative will attend the annual National EHDI conference for the purpose of sharing the latest information and collaborating with other experts in the field of early hearing los on best practices in early hearing detection and surveillance. A final VaCHISIP II report will be completed and published online to share with national EHDI stakeholders.

Other Collaboration Efforts. Collaboration with other sources is described elsewhere in this application. Specifically, collaboration with (1) Vital records is via EBC integration (see

Part 1, Background, VaCHISIP I); (2) Birth defects registry is via VISITS I and II Birth Defects modules (see Part 1, Background, Integrated Data System and VaCHISIP I, Part 1 G3 OB 5); (3) Immunization services is via potential data access and linking (see Part 1, Needs Assessment, Audiologic Assessment and Diagnostic Evaluation, and Part 2 G 1 OB 1 and G 3 OB 1); (4) Bloodspots programs via VISITS I and II Birth Defects modules (diagnosed case data are loaded into VISITS); (5) Part C EI via VISITS II automatic/semi-automatic referrals to the Part C EI database and LC activities (see Part 1, Background, VaCHISIP I, and Part 2 G 2 OB 3).

PART 4. PROGRAM CAPACITY

The following resources, program infrastructure, current and prior VEHDIP experience, and VEHDIP tracking and surveillance activities provide evidence that VDH has the resources, organizational structure, and technical capacity to successfully complete VaCHISIP II activities.

State and Local Resources

VEHDIP Advisory Committee. VaCHISIP II will be developed, implemented, and evaluated with input from state and local individual and organization stakeholders via the VEHDIP Adv Cmt, as described under Part 3, Collaborative Efforts.

VISITS Work Groups. New external VISITS user groups—audiologists and birthing center staff—will be convened to provide input into the development and testing of any new VISITS modules or other system modifications.

VISITS Development Team. VISITS II redesign is being completed by OIM; the same team will be involved in the development of new VISITS modules or modifications.

Program Infrastructure

VaCHISIP Work Group. The VaCHISIP Work Group will be established and modeled after other PSGS grant teams that have successfully planned, implemented, and evaluated similar

federally-funded projects. As previously done with other PSGS grant teams, the Work Group will be chaired by the VaCHISIP PD and will include those who have specific project responsibilities as well as ad hoc members who will provide consultation and technical assistance as needed. The Work Group will be convened monthly to ensure that the project stays within established time frames. During each meeting, members will review the Work Plan, provide updates on completing assigned activities, identify problems and barriers to accomplishing activities, and develop solutions to such obstacles, all of which will be documented on the VaCHISIP II Monthly Progress Report. This documentation, along with VaCHISIP Work Group meeting minutes, will be used for writing progress reports requested by CDC and will serve as reference materials for other such requests.

OFHS Research and Evaluation Team (RET). The OFHS RET provides an existing mechanism for the VaCHISIP Work Group to receive consultation and technical assistance on developing, administering, and analyzing VaCHISIP II surveys and evaluation reports.

Other VDH Program Areas. The Office of Minority Health provides a mechanism for the VaCHISIP Work Group to receive consultation and technical assistance on ensuring that any materials developed under VaCHISIP II are culturally and linguistically competent. The Public Relations Team is available to provide consultation and technical assistance to the Work Group on developing quality promotional materials. Bright Futures Coordinators are available to assist the Work Group in further incorporating EHDI processes within Virginia Bright Futures, which fosters partnerships between families, health professionals, and communities.

PSGS and VEHDIP Experiences

Cooperative Agreements. **In recent years, PSGS—with assistance and consultation from the VEHDIP Adv Cmt, the Virginia Genetics Advisory Committee, OFHS RET, and through contractual agreements with academic institutions—has been awarded and successfully managed the following cooperative agreements:**

(1) HRSA MCHB 4-year cooperative agreement related to hearing screening, 9/1/2001 – 8/31/2005; (2) HRSA MCHB 3-year cooperative agreement related to hearing screening, 9/1/2005 – 8/31/2008; (3) CDC 3-year cooperative agreement related to birth defects prevention and surveillance, 3/1/2002 – 2/28/2005; (4) CDC 5-year cooperative agreement related to birth defects prevention and surveillance, 3/1/2005 – 2/28/2010; (5) CDC 3-year cooperative agreement related to EHDI tracking, surveillance, and integration, 7/1/2005 – 6/30/2008.

VEHDIP-Specific Successes. **In recent years, VEHDIP—with assistance and consultation from the VEHDIP Adv Cmt, OFHS RET, VDH Public Relations Team, and through contractual agreements with academic institutions—has managed the successful completion of the following projects: (1) published and distributed annual reports using VISITS data; (2) developed a parent information poster that was featured in the 2004 Winter issue of *Parent* and disseminated to local health departments and pediatric practices; (3) completed a videotaped version of the resource guide entitled "Information for Parents of Children With Hearing Loss, Virginia's Resource Guide for Parents"; (4) completed a training initiative to increase the capacity of providers of early intervention services to deliver appropriate services to infants and young children who have hearing loss and their families; (5) established the Virginia Hearing Aid Loan Bank, which makes available select digital/programmable hearing aids and FM systems for children with hearing loss who are under 3 years of age; (6) established the Virginia Guide-By-Your-Side program, which was designed to meet the needs of parents of children newly-diagnosed with hearing loss by matching them with other parents with the same prior experience; (7) completed participation in the 5-state CDC-EHDI research project entitled "Lost to Follow Up – CDC 1% Evaluation Project"; and (9) collaborated with the Virginia Head Start Health Advisory Committee to provide hearing screening and follow-up services in Early Head Start programs.**

PART 5. STAFFING AND MANAGEMENT PLAN (10 points)

The following individuals will be members of the VaCHISIP Work Group and responsible for performing various assigned activities that are described in the VaCHISIP II Work Plan. For specific information about each individual, see Attachment 3. Biosketches. For

specific information about each position, see Attachment 4. Position Descriptions. For organizational structure, see Attachment 5. Organizational Charts.

PSGS Director. Nancy Ford is the current PSGS Director, which is a state full-time equivalent (FTE) position. As the VaCHISIP I PD and the supervisor of the VaCHISIP II PD, this individual will provide oversight to ensure the project is carried out according to CDC requirements and will be a co-writer of continuation applications and required reports. PSGS Director services for VaCHISIP II will be in-kind support.

VaCHISIP II Project Director (PD). Gayle Jones is the current VEHDIP Program Manager, which is a state FTE position. As the VaCHISIP II PD, this individual will provide direction for the project and be responsible for managing and performing activities described in the Work Plan under PD activities. PD services for VaCHISIP II will be in-kind support.

VaCHISIP II Project Coordinator (PC). A VaCHISIP II PC 1500-hour wage grant-restricted position will be established within VEHDIP. This individual will be responsible for performing PC activities described in the Work Plan. PC services for VaCHISIP II will be funded by this cooperative agreement.

VaCHISIP II Follow-up Analyst (FA). A VaCHISIP II FA 1500-hour wage grant-restricted position will be established within VEHDIP. The FA will be responsible for performing FA activities described in the Work Plan. FA services for VaCHISIP II will be funded by this cooperative agreement.

VEHDIP Follow-up Coordinator (FC). Ruth Frierson is the current VEHDIP FC, which is a state FTE position. FC services for VaCHISIP II will be in-kind support.

VEHDIP Surveillance and Evaluation Coordinator (SEC). Michelle Ballard is the current VEHDIP SEC, which is a state FTE position. The SEC will be responsible for

performing activities described in the Work Plan under SEC. SEC services for VaCHISIP II will be in-kind support.

VEHDIP Follow-up Specialist (FS). Lou Lambert is the current VEHDIP FS, which is a grant-restricted state FTE position. The funding source is the current HRSA MCHB UNHS cooperative agreement, which ends 8/30/2008. The FS will continue in this position pending award of the new HRSA MCHB cooperative agreement.

VEHDIP Quality Improvement Coordinator (QIC). The QIC position will be a grant-restricted 1500-hour wage position. The funding source will be the new HRSA MCHB UNHS grant, which, if awarded, will begin 9/1/2008. The QIC will be responsible for performing QIC activities described in the Work Plan. QIC services for VaCHISIP II will be in-kind support.

PART 6. EVALUATION PLAN

Comprehensive Project Evaluation. PC, with assistance from VaCHISIP II Work Group, will complete monthly progress reports on activities accomplished, barriers to achieving them, and steps to address the barriers. Quarterly summary reports will be presented to the VEHDIP Adv Cmt during its quarterly face-to-face meetings to identify gaps that are occurring, discuss how those gaps might best be addressed, and provide assistance in accomplishing certain activities. PD will adjust activities based on VEHDIP Adv Cmt feedback.

Surveillance and Evaluation Plan. The process of increasing the effectiveness and efficiency of the VEHDIP surveillance system to promote the best use of public health resources will continue by (1) developing a plan to implement VEHDIP Evaluation Report recommendations to improve quality and efficiency, (2) developing a VEHDIP Surveillance and Evaluation Plan for implementation on a long-term basis, and (3) engaging stakeholders to monitor progress and support improvement efforts. See Action Plan 3, G3 OB 4 and G3 OB 5.

Progress Towards Goals. The following evaluation measures will assess to what extent VaCHISIP goals and objectives are met.

Goal 1 OB 1 Measure 1: Percent of "initial hearing screening of out-of-hospital births" reports that are sent to VDH via VISITS II and which are without data errors and omissions is increased.

Goal 1 OB 1 Measure 2: Percent of "follow-up screening on infants who fail their initial hearing screening" reports that are sent to VDH via VISITS II and which are without data errors and omissions is increased.

Goal 1 OB Measure 3: Percent of "diagnostic evaluation" reports that are sent to VDH via VISITS II and which are without data errors and omissions is increased.

Goal 1 OB 1 Measure 4: Percent of referrals on infants diagnosed with hearing loss or hearing impairment to early intervention by 6 months of age sent to Part-C via VISITS II is increased.

Goal 1 OB 1 Measure 5: All activities listed under G1 OB 1 are accomplished.

Goal 1 OB 2 Measure 1: All new VISITS modules or other system modifications meet HIPAA and VDH Internal Audit Department Information Systems Security Requirements.

Goal 1 OB 2 Measure 2: All activities listed under G1 OB 2 are accomplished.

Goal 2 OB 1 Measure 1: Percent of initial hearing screens on out-of-hospital births is increased.

Goal 2 OB 1 Measure 2: All activities listed under G2 OB 1 are accomplished.

Goal 2 OB 2 Measure 1: Percent of infants receiving evaluation/diagnosis by an audiologist by 3 months of age is increased.

Goal 2 OB 2 Measure 2: All activities listed under G2 OB 2 are accomplished.

Goal 2 OB 3 Measure 1: Percent of diagnosed infants receiving early intervention services by 6 months of age is increased.

Goal 2 OB 3 Measure 2: All activities listed under G2 OB 3 are accomplished.

Goal 3 OB 1 Measure 1: VISITS II data are linked or matched with EPSDT Medicaid data.

Goal 3 OB 1 Measure 2: All activities listed under G3 OB 1 are accomplished.

Goal 3 OB 2 Measure 1: Percent of lost to follow up infants is reduced.

Goal 3 OB 2 Measure 2: Percent of lost to follow up infants identified in other child health databases is increased.

Goal 3 OB 2 Measure 3: All activities listed under G3 OB 2 are accomplished.

Goal 3 OB 3 Measure 1: Percent of children identified with late onset or progressive hearing loss not known to VEHDIP is increased.

Goal 3 OB 3 Measure 2: All activities listed under G3 OB 3 are accomplished.

Goal 3 OB 4 Measure 1: Percent of duplicated cases in VISITS II is reduced.

Goal 3 OB 4 Measure 2: All activities listed under G3 OB 4 are accomplished.

Goal 3 OB 5 Measure 1: Percent of expected hearing loss cases in VISITS II is increased.

Goal 3 OB 5 Measure 2: All activities listed under G3 OB 5 are accomplished.