

Project Abstract

Project Title: Virginia Reducing Loss to Follow-up Project (VRLFP)
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Problem: While the lost to follow-up rate has steadily decreased from 78% (2009) to 8.3% (2012), (a decrease of 89%), and the age at diagnosis of hearing loss has decreased from 199 days in 2011 to 129 days in 2012, the number of infants diagnosed with permanent hearing loss only increased by 17, from 160 to 177. With the rate of lost to follow-up drastically decreasing, we expect to see a substantial increase in the number of infants diagnosed with hearing loss. However, Virginia is currently diagnosing and reporting fewer than 2 infants per 1000 births with hearing loss, less than the expected national rate of 3 per 1000 births. This indicates a gap in the VEHDIP process of diagnosing and reporting. Additionally, the rate of referral to early intervention (EI) services has increased by 44%, from 68% of children with hearing loss referred to EI in 2010 to 98% referred in 2012. However, the rate of enrollment in EI has only increased by 21% from 34% (2010) to 41%. This clearly outlines a problem in enrollment or a problem with documentation of enrollment.

Goals and Objectives: The overall goal of the VRLFP is to maintain the gains achieved through effective follow up and improve the loss to documentation/loss to follow up at each stage of the EHDI process by assuring a sustainable structure for process improvement and utilizing targeted quality improvement methodologies. Project goals include:

- Develop an infrastructure to initiate and continue systems of change;
- Maintain, update, and improve effective education activities and follow-up processes;
- Use the Plan Do Study Act (PDSA) systems change process to reduce loss to follow up and loss to documentation at each stage of the EHDI process.

Methodology: Follow-up staff will continue to track and follow up on infants with a failed result and children with no documented diagnosis. The project will use proven quality improvement methods to further identify barriers at each phase of the EHDI process and propose interventions. A Quality Improvement Coordinator will be hired to implement the PDSA activities to test the interventions. Use of social media for public outreach/education will continue and new methods for education will be added, as recommended from PDSA findings. Stakeholders that currently have minimal or no engagement in the VEHDIP process (e.g., WIC clinics, birthing centers, otolaryngologists) will be brought into the project.

Evaluation: VRLFP will use the PDSA Model for Improvement, surveillance of data and outcome measures from the Virginia Infant Screening & Infant Tracking System (VISITS), to evaluate effectiveness, and a survey of providers will be conducted.

Annotation: The VRLFP's focus is to reduce lost to documentation and follow-up by leveraging existing resources and engaging new partners in implementing and evaluating small cycles of change to close identified and suspected gaps in the VEHDIP process.

PROJECT NARRATIVE

INTRODUCTION

The purpose of the Virginia Reducing Loss to Follow-up Project (VRLFP) is to reduce the number of infants who are lost to Virginia Early Hearing Detection and Intervention Program (VEHDIP) follow-up services – hearing rescreening, diagnostic evaluation, and early intervention services, following a missed screening or failed newborn hearing screening.

This will be accomplished by (1) developing an infrastructure to initiate and continue systems of change; (2) maintaining, updating, and improving effective education activities and follow-up processes; and (3) using the PDSA systems change process to reduce loss to follow up and loss to documentation at each stage of the EHDI process.

NEEDS ASSESSMENT

Overall, Virginia has dramatically improved follow-up screening and reporting. However, data indicates that there are several gaps in the follow-up process that require further exploration, analysis, and improvement.

In 2012, 101,412 births occurred within the Commonwealth of Virginia. Of these, 99,767 (98.4%) were documented as screened for newborn hearing loss. This high percentage of children screened represents progress in the VEHDIP process. In accordance with national EHDI goals, children should receive final hearing screening results by 1 month of age, have a complete diagnostic evaluation by 3 months of age (if they do not pass hearing screening), and children with a hearing loss should be enrolled in early intervention services by 6 months of age. At each of these stages, loss to follow-up remains a concern.

Virginia has made great progress in decreasing loss to follow-up at the screening stage. According to VEHDIP protocols, children who fail their initial hearing screening can be re-screened and may pass, without need for further follow-up, at that time. The percent of children who are lost to follow-up after failing an initial hearing screening has decreased dramatically: in 2012, 8.2% of children were lost to follow-up at screening, down from 79% in 2009. Significant improvements to the EHDI information system, integration with the electronic birth certificate, the increase in and targeted activities of follow-up staff, and public awareness activities have contributed to these notable improvements.

Despite these improvements, the number of infants *diagnosed* with permanent hearing loss only increased by 17, from 160 to 177. With the rate of lost to follow-up drastically decreasing, there should be a substantial increase in the number of infants diagnosed with hearing loss. However, Virginia is currently diagnosing and reporting fewer than 2 infants per 1000 births with hearing loss, less than the expected national rate of 3 per 1000 births. This indicates a gap in the VEHDIP process of diagnosing and reporting. Additionally, the rate of referral to early intervention (EI) services has increased by 44%, from 68% of children with hearing loss referred

to EI in 2010 to 98% referred in 2012. However, the rate of *enrollment* in EI has only increased by 21% from 34% (2010) to 41%. This clearly shows a problem in enrollment or a problem with documentation of enrollment.

Several socio-demographic factors were examined for a possible relationship to loss to follow-up at the diagnosis stage: race, maternal education and insurance type at delivery. The rate of loss to follow-up among each of these groups was compared to rates among non-members of the group; chi-square analyses were used to test for statistically significant differences (see Table 1).

Race was categorized into 4 groups: white, black, Hispanic, and other. There was no association between being white or black and loss to follow-up; babies within those groups were no more or less likely to be lost to follow-up than non-white or non-black babies, respectively. However, Hispanic babies were less likely than non-Hispanic babies to be lost to follow-up (42.2% vs. 53.2% lost to follow-up, $p < .05$). Babies of other races (including Asian, Native American, and Pacific Islander) were also less likely than other babies in the state to be lost to follow-up (44.1% vs. 53.3%, $p < .05$). Although these racial groups make up a small proportion of Virginia's total population, they are more likely to receive follow-up with an audiologist after a failed hearing screening.

Maternal education was also related to loss to follow-up. Babies whose mothers had a high school education or less were more likely to be lost to follow-up than babies whose mothers had education beyond high school (57.0% vs. 46.2%, $p < .001$). Mothers who received Medicaid assistance were more likely to be lost to follow-up than mothers with other types of insurance (56.8% vs. 47.1%, $p < .01$). Conversely, women with private insurance were less likely to be lost to follow-up than other mothers (46.7% vs. 55.9%, $p < .01$). There was no relationship between loss to follow-up and not having health insurance ($p = .90$).

Table 1. Loss to follow-up after failing final screening

	Percent	<i>p</i> -value
Race/Ethnicity		
White	55.2%	not significant
Black	54.1%	not significant
Hispanic (all races)	42.2%	< .05
Other	44.1%	< .05
Maternal education		
High school or less	57.0%	< .001
More than high school	46.1%	<.001
Insurance at delivery		
Medicaid	56.8%	< .01
Private	46.7%	< .01
Self-pay (no insurance)	50.0%	not significant
Total lost to follow-up	52.1%	

Access

VEHDIP no longer maintains a state-specific database of recognized diagnostic facilities. Audiologists interested in being a recognized follow-up diagnostic facility are referred to the national Early Hearing Detection & Intervention – Pediatric Audiology Links to Services (EHDIPALS). This is a national web-based directory of facilities that offer pediatric audiology services. Audiologists are contacted by VEHDIP staff to encourage them to complete the series of qualification questions to determine if they meet the requirements to be an approved diagnostic facility. There are approximately 150 audiological facilities in the state. VEHDIP reached out to all facilities to encourage registration on EHDIPALS, and additional recruitment and registration efforts were made with 59 facilities. However, only 38 facilities have registered, and of those only 35 are noted as approved facilities. This is 20 fewer than the 55 sites previously recognized by VEHDIP and represents documented compliance with diagnostic capacity consistent with nationally recognized protocols.

This shortage of approved audiology facilities is a barrier to accessing follow-up services in a timely manner because families have to travel a distance to reach the nearest appropriate facility. Approved audiology facilities have communicated their frustration with testing children of families that have to travel such long distances; they report that these infants are unprepared for testing, having slept during travel and arriving wide awake for testing. Families who are unsuccessful in obtaining the necessary follow-up test may not repeat the experience, resulting in infants lost to VEHDIP documentation. There is an ongoing need to educate parents about properly preparing infants for follow-up testing, particularly where they have to travel 10 miles or more to a pediatric audiology facility.

Families that live in areas where there are approved audiology facilities, such as Northern Virginia, also face access challenges. In this case, families may experience a delay in scheduling follow-up appointments because the demand for diagnostic audiological testing outpaces the capacity to provide services in a timely manner. Although EHDIPALS has proven to be a valuable resource, and VEHDIP staff use this resource daily to identify the nearest pediatric location and share this information with parents and providers, more efforts have to be made to increase the number of approved facilities. Parents and stakeholders are using this site to search for an approved follow-up facility; to date 3,220 parents have searched the Virginia EHDIPALS website and 1,396 of those are unique visitors, an additional 1,828 unique visitors have visited the site, and the site has been viewed a total of 63,267 times. This highlights the need to assure that the site can promote sufficient resources for all parents across Virginia. This presents an opportunity for VEHDIP to continue efforts to educate audiologists about the need for appropriate pediatric audiology services and recruit audiologists to register on EHDIPALS.

As one means to address access issues in underserved areas, VEHDIP has begun to implement tele-audiology through collaboration with the University of Virginia (UVA) Tele-Health Center. The VEHDIP Advisory Committee (AC) Health Disparity Workgroup is currently assessing the effectiveness of tele-audiology as a response to the shortage in pediatric audiology facilities. Given the successful track record of the UVA program in reaching underserved parts of the state, tele-audiology holds promise for serving families in rural areas, or those with significant transportation issues.

Extended Hospital Stays

Hospitals report newborn hearing screening results to VDH through the Virginia Infant Screening & Infant Tracking System (VISITS). The logic built into VISITS does not facilitate reporting screening results prior to discharge. Rather, all follow-up communication and activities are triggered at the time of discharge. This logic was built into the system to:

- (1) Avoid any opportunities for error in communicating follow-up recommendations to a parent of a child that has expired;
- (2) Prevent any possibility of communicating with parents of a child in a fragile health condition; and
- (3) Eliminate unnecessary communication to parents.

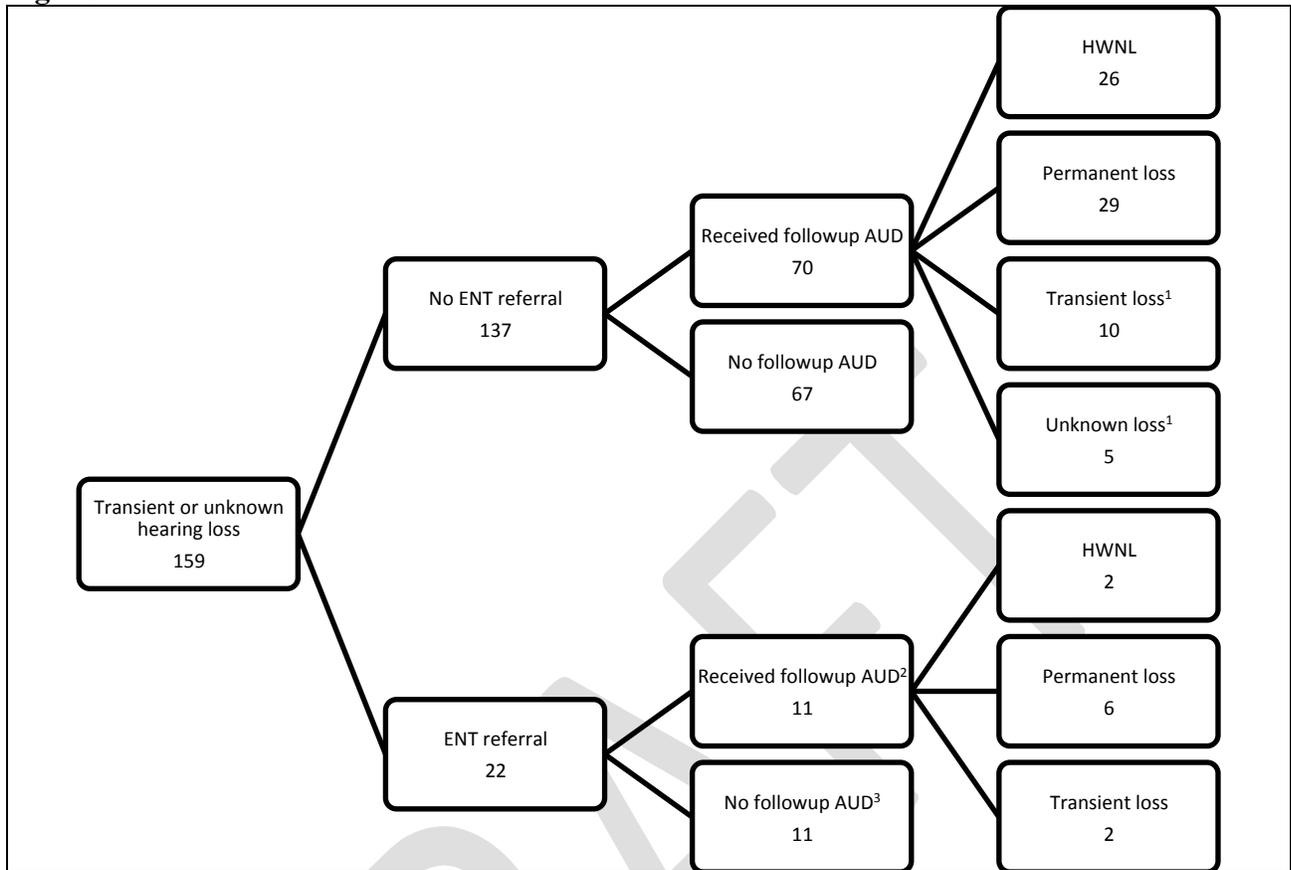
Infants with extended hospital stays therefore receive a hearing screening immediately before discharge in an effort to ensure an accurate assessment of the child's ability to hear after all medical interventions and medications have been administered. As a result, all infants with hospital stays greater than 30 days will fall outside the screening goal. Furthermore, since these are among the infants at highest risk for hearing loss, the compromised ability to capture and report their at-risk status contributes to their loss to follow up and documentation. Hospital staff, administrators, hearing screeners, and neonatologists have requested clearer guidance on timelines for testing and reporting these babies.

While the logic in VISITS continues to be valid, the need to provide clearly defined screening processes for infants with extended stays is a gap that must be addressed. The Project Director (PD) and VEHDIP AC have convened a workgroup of stakeholders to evaluate the feasibility of developing protocols and revising VISITS to address this need and facilitate appropriate and timely screening, possibly diagnosis, and reporting of these infants. This presents a clear opportunity for quality improvement steps to identify and promote best-practice in addressing this issue.

Problematic Diagnoses

Another area for improvement exists with the group of infants who receive a diagnosis of transient or unknown hearing loss. These diagnoses require further testing with an audiologist to determine whether the child has hearing within normal limits or a permanent hearing loss. However, only 51% of children born in Virginia in 2011-2012 with a transient or unknown hearing loss received the necessary follow-up evaluation. Of these, 25% still did not receive a final diagnosis of permanent hearing loss or confirmation of hearing within normal limits. Referring children with transient or unknown hearing loss to an otolaryngologist (ENT) does not improve the chances of follow-up: of the 22 children referred to an ENT after a transient or unknown diagnosis, only half completed further evaluation (see Figure 1). Working with these specialty physicians to explore opportunities for improvement represents a significant need for the program.

Figure 1



Medical Home

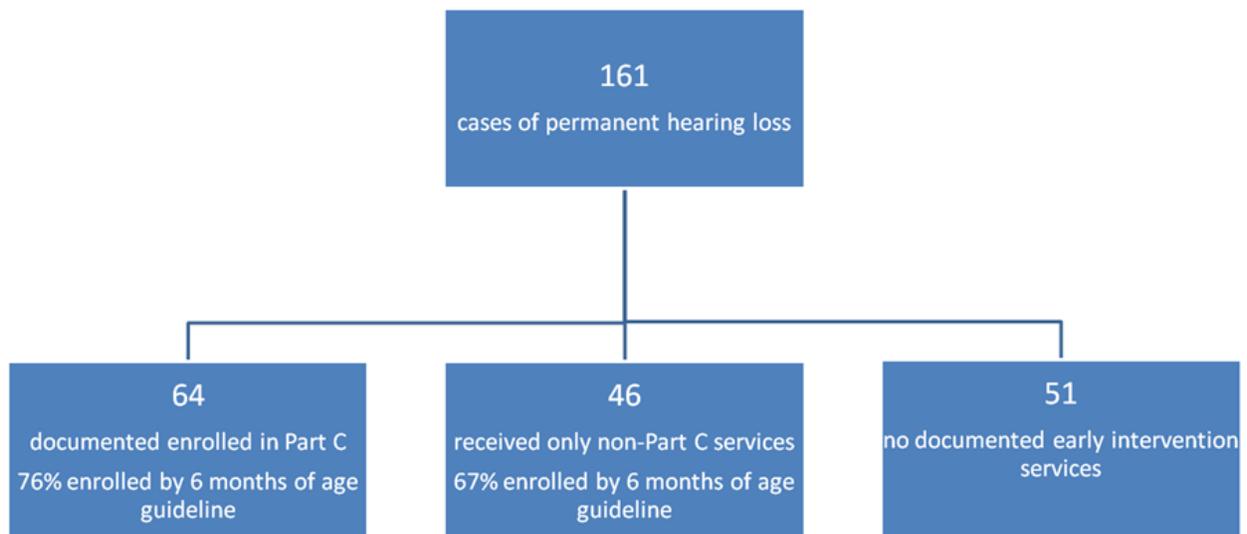
Primary care physicians have repeatedly requested electronic reporting of newborn hearing screening results. VDH determined the most efficient method of providing this would be through linking VISITS to the Virginia Immunization Information System (VIIS). This linkage, scheduled for completion in mid-2014, will enable direct sharing of initial hearing screening and rescreening results, and provide updates on diagnostic testing, with the infant’s medical home. The extent to which this will influence the number of infants diagnosed is unknown, and needs to be monitored carefully. A subsequent phase of this linkage will enable VEHDIP staff to receive confirmation on the child’s medical home, which should facilitate more expedient follow-up and referral to EI. Assessing and enhancing the efficiency and efficacy of these linkages, and the impact on 1-3-6 goals, presents another opportunity for improvement.

Early Intervention

Enrollment of children diagnosed with hearing loss into Part-C Early Intervention services continues to be a concern. Collaborative efforts between VDH and the Department of Behavioral Health and Development Services (DBHDS) have yielded an increase in the rate of enrollment by 21% from 2010 to 2012. However, the rate of referral to EI increased by 44%

during the same time period, indicating that there is still a gap in the process (see Figure 2). In an effort to further improve timely enrollment, VDH and DBHDS have designed an automatic referral process, expected to be released late summer 2014. This enhancement to VISITS will generate an email to the local EI Coordinator the morning after data has been entered in VISITS as a child diagnosed with a permanent hearing loss, alerting the Coordinator that a child eligible for services has been referred to their program. The Coordinator will be given access to VISITS to obtain and print the information needed for evaluation and enrollment into services. Infants and children referred will remain on a report, specific to each local system, until such time as enrollment information is provided back to VEHDIP through this automated process. EI Coordinators can also report if the family declines services, when and why the family declined services. The next phase of this automated process will include surveillance reports on referral and enrollment activities available for generation and review by each local system and by the VDH. VEHDIP will monitor this automated process every 3 months, in the first year, in order to assess any necessary revisions to assure the system is user friendly and maintain data quality. Like the VISITS-VIIS linkage, this new process offers VEHDIP circumstances to improve quality.

Figure 2



Family Involvement and Support

In 2006, VEHDIP established a family- to-family support system -- the Guide By Your Side® (GBYS) program, which connects parents of children who have been newly diagnosed with hearing loss to other parents who have already had that experience. In addition to general support, this program provides unbiased information on language and communication options for families living with a hearing loss. Most recent data demonstrates the need for such services;

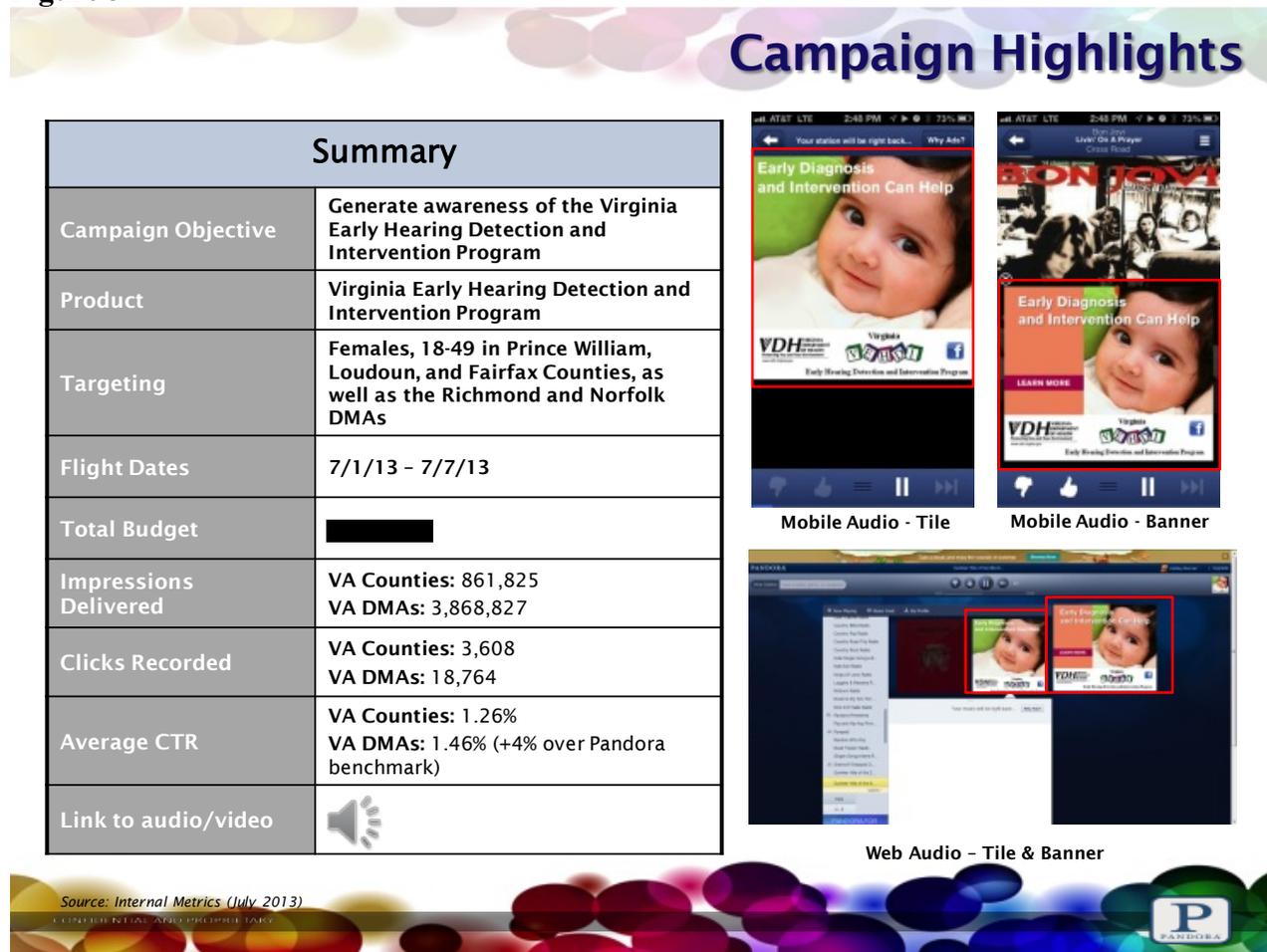
between August 2012 and December 2014, 130 families have received services from GBYS. VEHDIP promotes the use of GBYS to families with a newly diagnosed infant and refers families to the GBYS Parent Coordinator. A survey conducted of parents that received services from GBYS shows that: 94% families are satisfied or highly satisfied with the services received from the Virginia GBYS program and 82% of parents found the information useful; 95% found the information on communication options helpful in making their decision. The GBYS participated in 33 events of which 13 were trainings of stakeholders and parents; provided education on EHDI goals and processes to 1,340 stakeholders; and developed 21 educational videos on various communication options and various parent perspectives (<http://vimeo.com/channels/493137>). Success of this program indicates a need for a continued family-to-family support system with the same objectives to (1) connect newly diagnosed families with experience parents, (2) identify additional opportunities for outreach, (3) expand services that are culturally appropriate, and (4) evaluate the effectiveness of these services. However, VEHDIP is in jeopardy of losing the GBYS program, since its current configuration does not meet the copy write requirements. Establishing a viable alternative is a significant need to further this important family support work.

Public Awareness and Outreach

VEHDIP has experienced exceptional success in public awareness through social media venues and Pandora internet radio. As of March 2014 the VEHDIP Facebook page <https://www.facebook.com/vehdi> has 3,447 “Likes” (the number of followers) with an average monthly “Reach” (the number of unique visitors who have seen at least one posting) of approximately 38,000 people. On average 1,266 people are reached daily, at a cost of [REDACTED] per day. VEHDIP piloted 15 second and 30 second Public Service Announcements (PSA) on Pandora internet radio for one week in 2013. VEHDIP PSA exceeded the industry’s own standard in “click” responses by 4%. The VEDHIP website received an average of 3,000 daily hits to its website during that week, representing a significant exposure to the program’s information (see Figure 3 to follow).

Use of social media warrants analysis of its effectiveness. The VEHDIP needs to explore further how to target this use to reach the most vulnerable populations, such as parents of extended hospital stay infants.

Figure 3



Summary

The key areas for improvement in the VRLFP center on: access to appropriate audiological diagnostic services; infants with extended hospital stays; infants with problematic diagnoses; and, reaching the highest risk populations – low income, low level of maternal education. Targeting interventions in these areas will improve the 1-3-6 measures overall.

In order to increase the number of infants diagnosed with hearing loss, and assure linkage to appropriate services, the VEHDIP recognizes that there are opportunities for new or enhanced partnerships with:

- Special Supplemental Nutrition Program for Women, Infants & Children (WIC)
- Home Visitors
- State Medicaid Office
- VDH Office of Minority Health and Health Policy
- Early Head Start and child care providers
- Birthing centers and midwives
- Social media outlets

METHODOLOGY

The proposed VRLFP will reduce the lost to follow-up of infants who did not have a newborn hearing screening, those not receiving a timely final diagnosis, and infants and children not receiving EI services by:

- Developing an infrastructure to initiate and continue systems of change;
- Maintaining, updating, and improving effective education activities and follow-up processes;
- Using the PDSA systems change process, to reduce loss to follow up at each stage of the EHDI process

VRLFP will identify a Quality Improvement Leadership Team (QILT) from existing VEHDIP Advisory Committee Workgroups, new stakeholders, and parents to develop Aim Statements, identify gaps in the VEHDIP System, implement improvement strategies, assess findings, review data, and provide recommendations. The QILT will implement a minimum of thirty PDSAs that include existing primary partners: hospitals, audiologists, early intervention providers, family-to-family support groups, consumers, parents, and pediatricians. Additional partners will be recruited and represented on the QILT based identified needs, to include: otolaryngologists (ENT), WIC staff, neonatologists, birthing center administrators, and midwives.

PDSAs will be used to test every area of the VEHDIP process and practice, with emphasis on the identified gaps:

- Infants with limited access to an approved audiologist;
- Infants with extended hospital stays;
- Infants that are Medicaid eligible and lost to follow-up;
- Infants with no medical home;
- Infants referred but not documented as enrolled in EI
- Stakeholders who will benefit from training on VEHDIP processes and resources.

Through the PDSA process VEHDIP will test the use of previously developed educational materials -- *Can Your Baby Hear?*, *What Does Your Baby Hear Now?*, and newborn screening posters -- with a variety of different audiences, to assess the usefulness and additional needs, and to determine the most effective time to share educational materials. The QILT will provide recommendations on changes in content, format, and process based on these findings.

The QILT will implement PDSA activities at every step of the VEHDIP process by reviewing:

- Existing follow-up process;
- Lost to follow-up data;
- Infants with missed initial screenings;
- Infants with extended NICU stays;
- Reporting of enrollment into Part-C Early Intervention services;
- Audiology screening, diagnostic evaluation and reporting process;
- Hospital screening, risk-assessment documentation, and reporting process;
- Process after referral to ENT physicians;

- Reporting of infants not born in a hospital;
- Process of reporting infants transferred;
- Referral to community resources process;
- Use of previously developed web-based trainings on VEHDIP;
- Public awareness activities; and
- Outcomes data.

Internet radio's advantage over conventional radio is that specific audiences can be targeted based on age, gender, and zip code. Additional benefits include a captive audience (ads cannot be skipped), a visual and audio experience, and easy "tap-in" feature to get more information, which facilitates evaluation of responses. VEHDIP plans to continue to use this outlet as a means to educate stakeholders and targeted audiences. PSAs will be developed and dissemination implemented based on findings and recommendations from the PDSAs conducted on the 1-3-6 follow-up process, as gaps are identified and best methods to meet those needs are developed.

VEHDIP will build on the success of the past Reducing Loss to Follow up Project by:

- Continuing to closely track and follow-up every infant with a missed screening and failed result;
- Reviewing and revising the VISITS reporting system logic;
- Enhancing the VISITS to increase use and automate existing manual processes;
- Decreasing the age of follow-up screening and diagnosis;
- Increasing access to available resources;
- Maintaining collaborative partnerships with stakeholders;
- Providing trainings on VEHDIP to different audiences in a variety of venues;
- Implementing public awareness activities through social media outlets; and
- Impacting behavior changes through timely education.

Site visits to 3 audiology facilities and 3 hospitals will be conducted to provide technical assistance, assess successful strategies, and identify opportunities for improvement. Follow-up staff will encourage audiologists to register on Early Hearing Detection and Intervention Pediatric Audiology Links to Services (EHDIPALS) to increase pediatric resources and access to follow-up screenings and evaluations in areas with high lost to follow-up rates. Families in need of follow-up service will be referred to EHDIPALS to obtain information on facilities equipped to provide the services needed. Identification of a medical home for infants in need of follow-up will continue to be a primary objective for follow-up staff. In addition to providing education to hospitals on the importance of capturing and reporting a medical home on every child in need of follow-up, staff will monitor and report on medical home identification through the VISITS-VIIS linkage.

Surveillance of loss to follow-up data continues to indicate that infants referred to ENT do not return for follow-up testing because (1) parents are not informed of the need for additional testing after medical clearance, and (2) parents do not see a need for follow-up testing. Using the PDSA process, follow-up staff and the QILT will assess current processes and education needs, and test strategies for improvement.

WORK PLAN

Goal 1: Develop an infrastructure to initiate and continue systems of change

Activities: By the end of Year One:

Obj 1: Assure appropriate staffing

- Project Director (PD) will recruit a qualified wage Quality Improvement Coordinator (QIC).
- QIC will become knowledgeable on VEHDIP processes and goals.

Obj 2: Establish a subgroup of the VEHDIP Advisory Committee to serve as the Quality Improvement Leadership Team (QILT);

- Identify core representatives to include at least: EHDI manager, pediatric audiologist, parent, pediatrician, EI administrator, epidemiologist.
- QIC in collaboration with QILT will identify new stakeholders (to include representatives from: Early Head Start, Early Childhood Comprehensive Systems Grant Coordinator, WIC, ENT, Maternal, Infant, and Early Childhood Home Visiting Grant Coordinator, Minority Health and Health Policy) as partners in meeting VEHDIP processes and goals.
- QIC will recruit new stakeholders onto the QILT.
- Develop meeting schedule.
- QIC will conduct training for QILT members on PDSA processes.

Obj 3: Review impact of previous QI actions taken (EHDI Learning Collaborative) and those not taken, including a focus on disparities (economic, geographic);

- PD will assure new stakeholders understand VEHDIP processes and goals.
- Follow up Specialist (FS) and QIC in collaboration with QILT will review existing tracking and follow-up process for infants with a failed initial screening.
- Follow up Specialist II (FSII) and QIC in collaboration with QILT will review existing tracking and follow-up processes for infants with more than one failed screening.
- Follow up Coordinator (FC) and QIC in collaboration with QILT will review existing EI referral and enrollment documentation of infants diagnosed with hearing loss.
- QIC in collaboration with QILT will review the existing referral processes for infants reported with a Permanent Hearing Loss, Unilateral Hearing Loss, Transient Hearing Loss, and Unknown Hearing Loss.
- Craft Aim Statements and charge QI Work Groups for each phase of VEHDIP processes.
- Develop monitoring process for Work Groups (to integrate with evaluation plan).

Activities: by the end of Year 2:

- QILT will maintain meeting schedule and oversight activities.
- QILT will monitor progress with PDSA projects implemented (see Goals 2 and 3).
- QILT and QIC will review Year 3 Work Plan; develop new PDSA projects as indicated.
- QILT will make recommendations to VEHDIP process changes based on Year 1 learning (e.g., modifications to VISITS, protocols).
- QILT and QIC will develop plan for statewide spread of best practices from Years 1 and 2.

Activities: by the end of Year 3:

- QILT will maintain meeting schedule and oversight activities.
- QILT will monitor progress with PDSA projects implemented (see Goals 2 and 3).

- QILT and VEHDIP staff will implement statewide spread plan based on PDSA findings and recommendations to include at minimum: statewide stakeholder conference to share best practices; mentoring system between successful providers and those with identified challenges; targeted public awareness and professional training and education.
- PD, QIC, and Policy and Evaluation (P&E) staff will conduct surveillance of data and activities at each step of the spread process.
- QIC and P&E staff will provide updates to the VEHDIP AC quarterly, on impact and outcomes of PDSA activities.
- VEHDIP AC will make recommendations for modifications to existing regulations, as indicated from process improvements.

Goal 2: Maintain, update, and improve effective education activities and follow up processes.

Obj 1: Assess the effectiveness of current educational materials

Activities: by the end of Year One:

- FS in collaboration with the QILT will implement a PDSA to assess the use and effectiveness of the “*Can Your Baby Hear?*” brochure by three hospitals.
- FS in collaboration with the QILT will implement a PDSA to assess the benefit of using the “*Can Your Baby Hear?*” brochure by two birthing centers and two midwives.
- FS II, in collaboration with the QILT, will implement a PDSA to assess the use and effectiveness of the “*What Can Your Baby Hear Now?*” brochure by two obstetrical providers.
- FS II, in collaboration with the QILT, will implement a PDSA to assess the effectiveness of the newborn screening “*Baby’s First To-Do List*” poster among five pediatric and family physician practices.
- FS, FSII, and FC continue to monitor birth hospitals and audiology practices for compliance with VEHDIP protocols.
- FS, FSII, and FC provide education and technical assistance to identified sites as needed.

Activities: by the end of Year 2:

- QIC will spread and test successful PDSA projects to at least 10 hospitals, birthing centers, and other provider groups.
- Continue to refine processes with additional PDSA projects as indicated.
- QIC and P&E staff will provide updates to the VEHDIP AC, quarterly, on impact and outcomes of PDSA activities.
- QIC and VEHDIP staff will make recommendations for statewide spread of successful improvement processes and tools.

Activities: by the end of Year 3:

- QIC and P&E staff will provide updates to the VEHDIP AC, quarterly, on impact and outcomes of PDSA activities.
- Continue to refine processes and tools as indicated.
- Implement statewide spread plan.
- PD, QIC, and P&E staff will conduct surveillance of data and activities at each step of the spread process.

Obj 2: Assess the effectiveness of current public awareness activities

Activities: by the end of year 1:

- FS and QIC will implement a PDSA to assess the use of social media.
- FS and QIC will identify additional areas to assess public awareness for infants with a missed screening, through the PDSA process.
- QIC in collaboration with QILT will develop a PDSA to target awareness among newly-identified stakeholders (e.g., child care providers, WIC staff).
- QIC will collaborate with the QILT to implement lessons learned from PDSAs and provide recommendations on increasing public awareness for infants with a missed screen.
- PD will collaborate with other State EHDI Coordinators to assess partnerships in their states that have proven successful in engaging infants lost to follow-up and at highest risk for lost to follow-up.
- PD will collaborate with the Office of Minority Health and Health Policy to assess potential activities to decrease lost to follow-up.
- FC and VEHDIP AC Health Disparities Workgroup will identify additional community partners serving high risk lost to follow-up families.
- FC and VEHDIP AC Health Disparities Workgroup will explore the potential for engaging Department of Medical Assistance Services (DMAS) to assess impact of Medicaid policies on the lost to follow-up rate.
- PD will collaborate with Federally Qualified Community Health Centers to identify potential outreach activities to families of infants at risk for lost to follow-up.
- FC will collaborate with the Department of Social Services to assess processes that may impact families at risk of lost to follow-up, such as entry into foster care, and child protective services.
- FC will assess findings of potential partnerships, possible collaborative activities, and expected impact of these partnerships on families of infants at-risk for lost to follow-up.

Activities: by the end of Year 2:

- QIC in collaboration with QILT will implement a PDSA to improve awareness among the new stakeholders.
- FC and VEHDIP AC Health Disparities Workgroup will develop an action plan to decrease the lost to follow-up rate among infants born to mothers with a high-school education or less that are Medicaid eligible.
- FC and VEHDIP AC Health Disparities Workgroup will develop a plan for addressing health disparities in EHDI through education and awareness.
- FSII and QIC will identify additional areas to assess public awareness for infants “in-process” without a diagnosis, through the PDSA process.
- QIC will collaborate with the QILT to implement lessons learned from PDSAs and provide recommendations on increasing public awareness for infants “in-process”.
- FS and QIC will develop recommendations for statewide spread of successful use of social media.

Activities: by the end of Year Three:

- QIC in collaboration with the QILT will develop lessons learned from PDSAs and provide recommendations on increasing public awareness.

- QIC and PD will conduct survey of partners to assess knowledge gained since inception of project.
- P&E staff will analyze survey and provide analysis to PD, VEHDIP AC, and QILT
- Implement statewide spread plan for use of social media.
- VEHDIP AC will develop educational content for future use with new stakeholders.

Goal 3: Using the PDSA systems change process, reduce loss to follow up at each stage of the EHDI process

Obj 1: Reduce from 8.3% to 3% the loss to documentation/follow up at the point of screening

Activities: by the end of year 1:

- QIC in collaboration with QILT will develop and implement PDSA activities in two – three hospitals for infants with a missed screening.
- QIC in collaboration with QILT will develop and implement PDSA activities with two – three primary care practitioners and audiologists for infants with a failed initial screening.
- QIC in collaboration with QILT will develop and implement PDSA activities in two – three hospitals for infants with extended stay in NICU.

Activities: by the end of Year 2:

- QILT will implement a PDSA to evaluate effectiveness of existing partnerships involved in pre-natal education about EHDI.
- QILT will implement PDSA on data-sharing of initial hearing screening results through the VISITS/VIIS linkage and determine impact on follow-up, tracking, reporting, and letter generation to parents and providers.
- QILT will implement PDSA on data sharing of hearing re-screening results through the VISITS/VIIS linkage and determine impact on follow-up, tracking, reporting, and letter generation to parents and providers.
- QILT will provide recommendations to PD for enhancement or revisions to VISITS/VIIS linkage based on findings from year 2 PDSAs.
- Spread and test successful PDSA pilots to at least 10 hospitals, birthing centers, primary care practitioners, and audiologists
- Continue to refine processes with additional PDSA pilots as indicated
- QIC and PD make recommendations for statewide spread of successful improvement processes and tools.

Activities: by the end of Year 3:

- Continue to refine processes and tools as indicated
- P&E unit staff will conduct analysis of medical home identification data through the VISITS/VIIS linkage.
- QILT will implement PDSA on identification of medical home through the VISITS/VIIS linkage.
- QILT in collaboration with VEHDIP AC Health Disparities Workgroup will implement PDSA to determine the impact of partnering with DMAS on families of infants at high risk for lost to follow-up
- QIC and P&E staff will provide updates to the VEHDIP AC, quarterly, on impact and outcomes of PDSA activities.
- Implement statewide spread plan.

- PD, QIC, and P&E staff will conduct surveillance of data and activities at each step of the spread process.

Obj 2: Reduce from 50% to 20% the loss to documentation/follow up at the point of diagnosis

Activities: by the end of year 1:

- QIC in collaboration with QILT will develop and implement PDSA activities with two – three primary care practitioners and audiologists for infants with more than 1 failed screening test.
- QIC in collaboration with QILT will develop and implement PDSA activities with two primary care practitioners or audiologists for infants referred to ENT specialists.
- QIC in collaboration with QILT will develop and implement PDSA activities with two – three hospitals and primary care practitioners for infants reported with Atresia of the ear.
- QIC in collaboration with QILT will develop and implement PDSA activities to test tele-audiology services in one area of the state.

Activities: by the end of Year 2:

- Spread and test successful PDSA pilots to at least 10 hospitals, birthing centers, and ENT specialists.
- Spread and test successful PDSA tele-audiology to one more area of the state.
- QILT will implement PDSA on data sharing of infants with “in-process” results; inconclusive, transient hearing loss, and unknown hearing loss, through the VISITS/VIIS linkage and determine impact on follow-up tracking, reporting, and letter generation to parents and providers.
- Continue to refine processes with additional PDSA pilots as indicated.
- QIC and PD will make recommendations for statewide spread of successful improvement processes and tools.

Activities: by the end of Year 3:

- Continue to refine and test processes and tools as indicated.
- QIC and P&E staff will provide updates to the VEHDIP AC, quarterly, on impact and outcomes of PDSA activities.
- Implement statewide spread plan.
- PD, QIC, and P&E staff will conduct surveillance of data and activities at each step of the spread process.

Obj 3: Increase from 41% to 76% the loss to documentation/follow up at the point of referral to Early Intervention (EI)

Activities: by the end of year 1:

- PD in collaboration with EI Program and Office of Information Management (OIM) will implement PDSA activities to test referral from VISITS to a subset of EI system for infants reported with Permanent Hearing Loss.
- QILT will implement PDSA on data sharing of hearing loss diagnosis through the VISITS/VIIS linkage and determine impact on referral and enrollment to early intervention services.

Activities: by the end of Year 2:

- Spread and test successful PDSA projects to at least 10 additional EI systems.
- Continue to refine processes with additional PDSA projects as indicated.

- QIC and PD will make recommendations for statewide spread of successful improvement processes and tools.

Activities: by the end of Year 3:

- Continue to refine and test processes and tools as indicated.
- Implement statewide spread plan.
- PD, QIC, and P&E staff will conduct surveillance of data and activities at each step of the spread process.
- QIC and P&E staff will provide updates to the VEHDIP AC, quarterly, on impact and outcomes of PDSA activities.

RESOLUTION OF CHALLENGES

The primary goals of the VRLFP are to ensure all infants receive initial screening, follow-up, diagnosis, and referral and enrollment to services in a timely manner, by closing gaps in the follow-up process. In preparation for implementation of activities to support this goal, the possible challenges and proposed resolution strategies are listed below:

Staff recruitment: The process of establishing a new position (Quality Improvement Coordinator) is a timely and extensive process that cannot be initiated until the funding is secure. This position is critical to facilitating the PDSA activities. The PD will prepare all necessary paperwork for establishment of this position in advance of receiving funds and will start working with VEHDIP staff and VEHDIP AC to establish the QILT in preparation for hiring of the QIC.

Sustainability of tele-audiology: Funds for establishing new tele-audiology sites are included in this grant budget; sustainability is a concern. Collaborative activities with the UVA Tele-Health Center have proven to be a contributing factor in facilitating tele-audiology services in VEHDIP and have allowed VEHDIP to leverage their funds by providing in-kind support of tele-medicine expertise and resources. VEHDIP will continue to collaborate with the UVA Tele-Health Center to expand tele-audiology services. Demonstrating effectiveness of tele-audiology to all partners, and promoting awareness of third-party reimbursement, will support sustainability beyond the grant period.

Engagement of new stakeholders: The gaps in the EHDI follow-up process will require that EHDI engage new stakeholders in order to identify strategies in addressing these gaps. Demands on stakeholders' time are high and involvement in EHDI might be an additional burden on their time. PD will make every effort to collaborate with new stakeholders at mutually convenient times, and use efficient communication technologies, to ensure stakeholders are represented and their contributions captured and taken into consideration in the development of improvement plans.

Limited resources: Virginia has chosen to participate and use the Early Hearing Detection & Intervention – Pediatric Audiology Links to Services (EHDIPALS) as its only source for approved audiology facilities. Although this has improved the quality of services provided to families, the number of approved facilities in Virginia decreased from 55 to 35. This will impact access to follow-up screening and diagnostic services and the ability of families to schedule follow-up testing in a timely manner. The VRLFP will continue to contact families immediately

to encourage prompt scheduling of follow-up appointments and staff will facilitate the scheduling of appointments whenever possible. Demonstrating success through PDSA improvement processes in scheduling audiology visits, and tele-audiology, will identify best practices for statewide spread.

EVALUATION AND TECHNICAL SUPPORT CAPACITIES

Comprehensive Project Evaluation

Comprehensive evaluation of the VRLFP will involve quantitative and qualitative measurement of objective-related outcomes. The primary data source for evaluation will be the VISITS database. All components of the EHDI 1-3-6 process will be evaluated, with special emphasis on current gaps; infants referred to ENT; infants with transient hearing loss, infants with unknown hearing loss, and infants with craniofacial anomalies.

Other components of the evaluation will be more objective specific and directly related to grant funded activities. Evaluation of the Plan, Do, Study, Act, quality improvement process will be conducted before and after each PDSA, to monitor impact of the small systems of change implemented. Additional evaluations will be conducted of the same PDSAs as successful changes are implemented more broadly. Surveys will be developed and conducted to assess awareness and knowledge of providers. Data reports will be extracted to evaluate public awareness activities, including reach, cost, and responses.

Evaluation Measures

The following evaluation measures will assess to what extent VRLFP objectives are met.

- 1) Decrease, by 10% each year, the proportion of infants with a missed screening.

Numerator: Infants born in Virginia who do not receive a hearing screening

Denominator: Occurrent births reported to Vital Statistics

Measure Frequency: Annually

Measure Source: Virginia Infant Screening and Infant Tracking System (VISITS)

- 2) Decrease, by 15% each year, the percent of children reported with transient or unknown hearing loss at most recent diagnosis.

Numerator: Children whose most recent diagnostic evaluation reports a “transient” or “unknown” status

Denominator: Children who fail their most recent hearing screening

Measure Frequency: Annually

Measure Source: VISITS

- 3) Increase the rate of documented enrollment into Part-C Early Intervention services by 5% in Year 1, and 15% in Years 2 and 3.

Numerator: Children with a signed Individual Family Service Plan (IFSP) with Part-C Early Intervention services

Denominator: Children with a permanent hearing loss who are current residents

Measure Frequency: Annually

Measure Source: Reports from Part-C Early Intervention, VISITS

- 4) Reduce the rate of loss to follow-up at the diagnosis stage by 10%.

Numerator: Children who fail their final hearing screening and have no documented diagnostic evaluation

Denominator: Children who failed their final hearing screening

Measure Frequency: Annually

Measure Source: VISITS

- 5) Increase the proportion of children who receive audiologic evaluation by 3 months of age after failing a final hearing screening by 10%.

Numerator: Children who fail their final hearing screening and receive an audiologic evaluation by 3 months of age

Denominator: Children who failed their final hearing screening

Measure Frequency: Annually

Measure Source: VISITS

- 6) Increase number of children diagnosed with permanent hearing loss by 10%.

Numerator: Children who fail their initial hearing screening and later receive a diagnosis of permanent hearing loss.

Denominator: N/A

Measure Frequency: Annually

Measure Source: VISITS

- 7) Increase the diagnosis follow-up rate among Medicaid eligible families by 10%.

Numerator: Children who fail their initial hearing screening and receive an audiologic evaluation

Denominator: Children whose births are covered by Medicaid

Measure Frequency: Annually

Measure Source: VISITS, Vital Statistics

- 8) Conduct trainings of EHDI providers (e.g., screeners, audiologists, ENTs) in EHDI best practices.

Numerator: Number of on-site trainings, number of completed online trainings

Denominator: N/A

Measure Frequency: Annually

Measure Source: EHDI program records, EHDI training website records

TECHNICAL SUPPORT CAPACITY

Project Personnel

The following individuals will be members of the VRLFP and will be responsible for performing various assigned activities that are described in the VRLFP Work Plan. VEHDIP includes two full-time and one part-time follow-up staff in addition to one program support staff. Staffing supports the *1-3-6 model* aiming to assure follow-up at each stage in the EHDI process. One additional part-time staff will be added to facilitate the PDSA activities. See Attachment 2 for Job Descriptions and Attachment 3 for Biographical Sketches of Key Personnel.

The VEHDIP **Program Manager/Project Director** (PD) has been in the position since 2009, having served as the Follow-up Coordinator since 2003. The PD's experience with the program makes this individual uniquely qualified to serve in this role. Under her leadership VEHDIP has experience significant improvements in follow-up and increased awareness of VEHDIP goals and processes. She supervises staff, coordinates the activities of the VEHDIP AC, participates in site visits, and partners with multiple stakeholders and providers on a daily basis.

The **VEHDIP Follow-Up Specialist** (FS) contacts parents and providers to assure re-screening and diagnostic evaluation as needed, prior to 3 months of age. Additionally, the FS works to identify a primary health care provider (medical home) for infants noted as not having one, updates and maintains primary health care provider information, provides technical assistance to providers on VEHDIP processes, participates in site visits to hospitals, collaborates on follow-up with birthing centers and border states, and monitors follow-up for infants born at home. FS implements and maintains public awareness activities through social media and is the liaison between VEHDIP and the VEHDIP AC Early Intervention Workgroup.

The **VEHDIP Follow-Up Specialist II** (FS II) (1500 hour wage position) contacts parents and providers to assure diagnostic evaluation prior to 3 months of age for infants with more than 1 failed result and infants report with a transient or unknown hearing loss. Additionally, the FS II works to identify an appropriate medical home for infants without one, provides technical assistance to providers on VEHDIP processes, and participates in site visits to audiology practices. The FS II assists with recruiting audiologists to register on the EHDIPALS site. FSII is the primary liaison between VEHDIP and the VEHDIP AC Audiology Workgroup.

The **VEHDIP Follow-Up Coordinator** (FC) contacts parents and providers to assure infants with a diagnosed hearing loss are linked to early intervention services prior to 6 months of age. Additionally, the FC contacts families of infants diagnosed with hearing loss 3 months after referral to services to ensure families are enrolled in services, identifies gaps in services, works to improve systems of support for families, and monitors the "1-3-6 Follow Plan" to ensure timely implementation. FC collaborates with the family to family support program, the Virginia Hearing Aid Loan Bank, and other community resources to ensure families receive timely

intervention services. FC is the primary liaison between VEHDIP and the VEHDIP AC Health Disparities Workgroup.

The **Quality Improvement Coordinator (QIC)** will collaborate with VEHDIP follow-up staff, VEHDIP AC, and stakeholders to convene the QILT team and will be responsible for facilitating quality improvement activities. QIC will coordinate all QILT and PDSA projects and will provide recommendations for revising EHDI processes and developing a plan for statewide spread of best practices. QIC will document all PDSA activities and work with P&E staff to evaluate data and perform analysis of activities.

Materials Published

In recent years, VEHDIP has developed and published the following materials:

Protocols: In 2011 VEHDIP revised all three health care provider protocols to align with the 2007 Joint Committee on Infant Hearing Recommendations: “Protocols for Medical Management,” “Protocols for Hospital Newborn Hearing Screening,” and “Protocols for Diagnostic Audiological Assessment.” The revised protocols were printed, sent to appropriate stakeholders, and published online.

Parent Brochures: VEHDIP extensively revised the following parent educational brochures: “*Can Your Baby Hear?*” and its Spanish translation “¿**Podrá Oír Su Bebe?**” The brochures were printed and made available to hospitals at no cost, to be given to parents at the time of their child’s birth, and were published online. VEHDIP also developed a new pre-natal brochure for parents: “*What Can Your Baby Hear Now?*” of which 5000 include a free baby lullaby CD. These brochures were printed and made available to Home Visitors, obstetrical offices, and pre-natal classes at no cost, to be given to parents during their pregnancy, and were published online.

Posters: VEHDIP developed and published the following educational posters: “Newborn Screening: Baby’s First To-Do List” and its Spanish translation “Primera Lista de Tareas de su Bebe” The posters were printed, sent to primary care providers and other stakeholders, made available to order at no cost, and published online.

Virginia’s Resource Guide for Families of Children with Hearing Loss: VEHDIP in collaboration with GBYS parents, and the Virginia Commonwealth University (VCU) Partnership for People with Disabilities developed a new resource guide for parents of children diagnosed with hearing loss. The guides were printed, sent to audiologists and parents of children reported to VDH with a diagnosed hearing loss, made available to order at no cost, and published online.

Parent Videos: Twenty-one parent videos were developed through the contract with VCU Partnership for People with Disabilities Virginia GBYS program (<http://vimeo.com/channels/493137>). To educate parents of children diagnosed with hearing loss on the different communication options and parents’ perspectives and experiences.

Previous Work of a Similar Nature

The VEHDIP has successfully completed numerous projects and activities of a similar nature to VRLFP. Specifically, the program was awarded and has successfully managed:

- A series of HRSA MCHB cooperative agreements related to hearing screening from 2001 – 2014, to include implementation of a Learning Collaborative for quality improvement; and,
- A series of CDC National Center on Birth Defects and Developmental Disabilities (NCBDDD) cooperative agreements related to birth defects prevention and surveillance, and EHDI tracking, surveillance, and integration from 2002 to 2014.

ORGANIZATIONAL INFORMATION

The mission of the Virginia Department of Health is to promote and protect the health of all Virginians. The agency's vision statement is "Healthy People in Healthy Communities." VDH is located in the Secretariat of Health and Human Resources that includes the departments of Behavioral Health and Developmental Services, Social Services, and Medical Assistance Services (Medicaid/Child Health Insurance Programs). In January 2013, Governor Terry McAuliffe reappointed William A. Hazel, Jr., M.D., to be Secretary of Health and Human Resources. Marissa Levine, M.D., M.P.H, serves as the Interim State Health Commissioner. Three deputy commissioners provide oversight for Community Health Services, Public Health and Preparedness, and Administration. See Attachment 6 for an Organizational Chart.

The Office of Family Health Services (OFHS) is the largest office in the agency based on the amount of funding received from multiple sources, the number of diverse programs provided, and the numbers of people served. The Office is composed of five divisions: Child and Family Health; Prevention and Health Promotion; Community Nutrition; Policy and Evaluation; and, Administration. In April 2014, Lillian Peake, M.D, M.P.H. will assume the role of OFHS Director.

OFHS submits, monitors, coordinates, and administers funds received from the Maternal and Child Health Block Grant and the Preventive Health and Health Services Block Grant, as well as approximately 50 categorical grants. While many grants are administered entirely within VDH, others are managed in partnership with other agencies or organizations in order to best meet the goals and objectives of the project. As a result, OFHS manages several hundred contracts and memoranda of agreements. The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), as well as Child and Adult and Summer Food Service Programs are managed by the Division of Community Nutrition. The OFHS Policy and Evaluation Division provides consultation, technical assistance, and analysis for maternal and child health policy, epidemiology, and surveillance, including such support for the VEHDIP. The OFHS Division of Administration is responsible for fiscal operations, procurement and contracting, human resource management, grants administration, and general administration. This Division has a close working relationship with the Agency's administrative offices (Fiscal, Budget, Purchasing and General Services, Internal Audit, Human Resources). This infrastructure ensures that programs are managed in compliance with federal and state policies and regulations.

The Office of Minority Health and Health Policy (OMHHP) identifies health inequities and their root causes and promotes equitable opportunities to be healthy. Under the leadership of Dr. Adrienne McFadden, OMHHP conducts analyses of the health disparities, identifies and promotes awareness of the social determinants of health, and provides education and consultation on evidence-based strategies across the agency and statewide.

VEHDIP resides within the Division of Child and Family Health (DCFH) in OFHS. DCFH operates numerous programs serving the maternal and child health populations including, but not limited to, the children with special health care needs programs, home visiting, newborn (blood spot) screening, and child development services. The DCFH is home to the Early Childhood Comprehensive Systems grant and the Maternal, Infant, and Early Childhood Home Visiting grant. The Child Health Programs Manager is the agency liaison to the Early Intervention Program in the Department of Behavioral Health and Developmental Services, and works with the Early Periodic Screening, Diagnosis, and Treatment program in Medicaid at the Department of Medical Assistance Services.

VEHDIP staff includes Ruth Frierson, Program Supervisor and Project Director for the VRLFP; Daphne Miller, Follow-up Coordinator; Katherine Gangeri, Follow-up Specialist; Anoinette Vaughan, Follow-up Specialist II; and, Darlene Donnelly, Program Support Technician. The current staff has been in place as a team for over two years. Ms. Frierson is bilingual in Spanish and English, which affords VEHDIP the opportunity to directly interact with Spanish-speaking parents and assist with written translation on materials. The VRLFP will add a wage Quality Improvement Coordinator to focus grant-funded projects and leverage the existing staffs' activities. Using the web-based reporting system VISITS, linked to the electronic birth record, staff are able to provide timely follow-up and monitor loss to follow up/documentation at all stages of the EHDI process. The VEHDIP is also supported by an Advisory Committee, established in the *Code of Virginia*, comprised of a wide range of active participants.

A previous VEHDIP grant supported an extensive Learning Collaborative. Through that effort, staff participated in quality improvement training, including use of PDSA systems of change. This Collaborative included five primary care practice sites and one speech/audiology practice. Lessons learned from this included: (1) developing a script for hearing screeners to share results with parents consistently across hospitals; (2) training of hearing screeners; and (3) obtaining alternate contacts for parents of children with failed results. As a result VEHDIP distributed the NCHAM Hearing Screening Curriculum Training to all hospitals that provides training on ways to deliver hearing screening results to parents and provides training on performing OAE and ABR screening. VISITS was revised to include alternate methods of contacting parents to include email and capturing of alternate contacts.

VEHDIP is, therefore, well positioned to garner necessary support and effect partnerships with key stakeholders to facilitate further quality improvement. See Attachment 5 for a Project Organizational Chart.