

An Evaluation of the Virginia Early Hearing Detection and Intervention Program

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Acronyms:

AAP: American Academy of Pediatrics
 CCC: Care Connection for Children
 CDC: Centers for Disease Control and Prevention
 DCAH: Division of Child and Adolescent Health
 EHDI: Early Hearing Detection and Intervention
 EI: Early Intervention
 FC: Follow-Up Coordinator
 FS: Follow-Up Specialist
 OFHS: Office of Family Health Services
 MCHB: Maternal and Child Health Bureau
 PCP: Primary Care Provider
 PD: Program Director
 PSGS: Pediatric Screening and Genetic Services
 PVP: Predictive Value Positive
 RTI: Research Triangle Institute
 SEC: Surveillance and Evaluation Coordinator
 VaCARES: Virginia Congenital Anomalies Reporting and Education System
 VDH: Virginia Department of Health
 VEHDIP: Virginia Early Hearing Detection and Intervention Program
 VISITS: Virginia Infant Screening and Infant Tracking System

INTRODUCTION

Surveillance is defined as the “systematic, ongoing assessment of the health of a community, based on the collection, interpretation, and use of health data and information.”¹ Surveillance data can be used for many purposes, including measuring the burden of a disease/health condition, monitoring trends, guiding program planning, prioritizing the allocation of resources, and providing a basis for research.

Evaluation is the “systematic investigation of the merit, worth, or significance of an object.”¹ A surveillance system is evaluated to assess how information has been disseminated to those who need to know and to ensure that it is addressing a problem of public health importance in an efficient and effective manner. Standard guidelines for evaluating surveillance systems have been published by the Centers for Disease Control and Prevention (CDC). This framework involves six steps: (1) engage the stakeholders in the evaluation; (2) describe the surveillance system to be evaluated; (3) focus the evaluation design; (4) gather credible evidence regarding the performance of the surveillance system; (5) justify and state conclusions, and make recommendations; and (6) ensure use of evaluation findings and share lessons learned.²

The purpose of this evaluation is to describe the degree to which the Virginia Early Hearing Detection and Intervention Program (VEHDIP) is meeting its objectives, serving a useful public health function, and operating effectively and efficiently. VEHDIP strives to conduct statewide surveillance of newborn hearing loss while fulfilling its purpose, which is to ensure that all infants are screened for hearing loss by 1 month of age, identify children with newborn hearing loss by 3 months of age and to assure enrollment in appropriate intervention services, including amplification, if needed, by 6 months of age.

PUBLIC HEALTH IMPORTANCE OF NEWBORN HEARING LOSS SURVEILLANCE

Indices of Frequency and Severity

Newborn hearing loss is a common birth defect, occurring in one to three of every thousand infants born in the United States. It is estimated that this amounts to 12,000 infants each year.³ The majority of these infants (9 in 10) will be born to parents without hearing loss. Seventeen of every 1000 children under age 18 have a hearing loss. Including adults, an estimated 28 million people in the United States have a hearing loss.⁴

Hearing loss can be categorized based on type, location, or severity. A conductive hearing loss is an impairment of the outer or middle ear, due to abnormalities or damage within the conductive pathways leading to the inner ear. This type of loss usually results in a reduction of sound level or a decreased ability to detect faint sounds.⁵ A hearing loss of the inner ear that results from damage to the sensory hair cells or the nerves that supply the inner ear is defined as a sensorineural hearing loss. Like conductive hearing loss, sensorineural hearing loss decreases the ability to detect sounds and reduces sound level, yet also affects speech comprehension or ability to hear clearly. Mixed hearing loss occurs when sensorineural loss and conductive loss exist concurrently.⁵

Hearing loss can also be defined based on whether one or both ears experience a loss. Unilateral loss occurs when hearing is impaired in one ear, while impairment in both ears is considered bilateral loss. A national survey of the hearing programs in 37 states and territories in 2004 found that of infants with hearing loss, 52% experienced a bilateral loss, 30% experienced a unilateral loss, and 18 percent were unspecified.³ In Virginia in 2004, approximately 69% of infants with hearing loss experienced a bilateral loss while 28% had a unilateral loss and 3% had an unspecified loss.

Sound is measured in decibels (dB), and severity of hearing loss is generally determined by the minimum number of decibels audible by each ear. The Directors of Speech and Hearing Program in State Health and Welfare Agencies define mild hearing loss as 21 dB to 40 dB, moderate loss as 41 dB to 70 dB, severe loss as 71 dB to 90 dB, and profound loss as 91 dB or more.⁶ With moderate hearing loss, a child will hear

very few, if any, speech sounds at normal speaking level, while with profound loss, a child will hear no speech and no other sound.³ Nationally, in 2003, similar percentages of unilateral and bilateral hearing loss were classified as severe (15-16%), but a larger percentage of unilateral hearing loss was mild (31% unilateral vs. 26% bilateral) or moderate (32% unilateral vs. 28% bilateral) while a larger proportion of bilateral hearing loss was profound (18% bilateral vs. 12% unilateral).³

Hearing loss often occurs in conjunction with other health conditions. An estimated 30% to 40% of individuals with hearing loss have comorbid conditions such as vision impairment or developmental disabilities that may include mental retardation, autism, or learning disabilities.⁷

Costs of Hearing Loss

The economic cost associated with developmental disabilities and impairments (such as mental retardation, cerebral palsy, vision impairment and hearing loss) is considerable. For children born in 2000, the total costs associated with hearing loss totaled \$1.9 billion (in 2003 dollars). Of this number, \$132 million were attributed to direct medical costs such as physician visits and assistive devices, \$469 million to direct nonmedical costs including special education and early intervention services, and \$1.3 billion to indirect costs such as lost productivity or premature mortality. In all, the average cost per individual with hearing loss was \$383,000.⁸

Newborn hearing screening is relatively inexpensive, costing approximately \$30 per child.⁹ Hearing screening equipment ranges from \$10,000 to 15,000. For hospitals, supplies and equipment calibration costs range from \$0.50 to \$10 per infant and personnel costs are approximately \$4.17 to \$12.50 per infant for a nurse/technician to perform the screening and \$10,634 annually for 25% of an audiologist/nurse full-time equivalent to coordinate the program. For audiologists providing diagnostic services, the cost estimate ranges from \$0.50 to \$1 per infant. Cost-effectiveness analyses have concluded that universal screening programs provide long-term cost savings when compared to selective screening or no screening. Universal screening programs offer early diagnostic capabilities that can yield a \$44,000 cost-savings per infant compared to selective screening, when hearing loss is diagnosed by 6 months of age.¹⁰

The cost of hearing loss in Virginia is shared by the government, insurance companies, and families of individuals with hearing loss. State legislation (*Code of Virginia* §38.2-3411.4) mandates that the initial newborn hearing screening and associated audiological evaluation are at no-cost to parents or guardians. However, this mandate does not cover individuals with self-insured health insurance policies, which are estimated to account for half of insured persons in Virginia. In addition, 7% of children in Virginia are uninsured.¹¹ The Early Periodic Screening Diagnosis and Treatment (EPSDT) Audiology and Hearing Program covers a range of services for children enrolled in Medicaid or Virginia's State Children's Health Insurance Program, Family Access to Medical Insurance Security Plan (FAMIS).¹² Rates of reimbursement were last revised in January 2008 and vary by type of hearing assessment or evaluation procedure. For example, the maximum reimbursement rate for a screening test, pure tone, air only is \$7.07 while the maximum rate for tympanometry is \$15.50. Insurance coverage for hearing aids and assistive devices such as cochlear implants is also a concern for many families. Under the EPSDT Audiology and Hearing Program, the maximum reimbursement rate for a hearing aid check is \$80 and the maximum rate for the diagnostic analysis of a cochlear implant ranges from \$43.79 to \$106.33. Recent Virginia data on private health insurance reimbursement of audiological services were unable to be obtained for this evaluation. However, a national study of the most common health management organization and preferred provider organization plans in 1998 found that 1% mentioned newborn hearing screening as a covered benefit, one-third covered audiologic evaluations, and approximately one-fifth listed tests and treatment as covered benefits. Many of these plans additionally restricted coverage to include services associated with a disease or injury, not a congenital condition.¹³ It is important to note that this study preceded the adoption of universal newborn hearing screening in many states, so it is likely that private insurance coverage has increased in recent years.

To address some of these cost barriers, VEHDIP has established the Hearing Aid Loan Bank, which lends hearing aids or FM systems for up to six months while children are in the process of securing permanent hearing aids. Also, uninsured or underinsured children at or below 300% of the Federal Poverty Level are eligible to

receive funding to purchase hearing aids through VDH's Children with Special Health Care Needs Pool of Funds.

Disparities/Inequalities Associated With Hearing Loss

Not much is known about disparities or inequalities with regard to newborn hearing loss diagnostic or intervention services. Potential disparities by sex, race/ethnicity, insurance status, education, or degree of urbanicity have been unable to be adequately assessed nationally or in the Commonwealth of Virginia. However, in Virginia in 2003, rates of followup between initial hearing screening and audiologic diagnostic evaluation were found to vary by health planning region. Southwestern Virginia had the lowest follow-up rate (71%) while Northwest Virginia had the highest (87%). In addition, the Eastern planning region appeared to have a disproportionate number of hearing loss cases compared to its number of births while Northern Virginia had the greatest number of births but fewer reported cases of hearing loss than Eastern Virginia.¹⁴

A few studies have been able to identify factors contributing to loss to followup in state-based or small population studies. In Massachusetts, being of non-white race/ethnicity, smoking during pregnancy, being covered by public insurance, and residing in the Western, Northeastern, or Southeastern part of the state were significantly associated with loss to followup on the use of audiologic evaluation services, after adjusting for infant birthweight, laterality of hearing referral, maternal age, marital status, and education. Infant factors were more strongly associated with loss to followup on the use of early intervention services. Infant low birthweight, unilateral hearing loss, mild or moderate hearing loss, and residence in Boston or Southeastern Massachusetts significantly increased the odds of loss to followup, after adjusting for maternal age, race/ethnicity, marital status, smoking during pregnancy, education, and source of delivery payment.¹⁵ In a hospital-based study in Maryland, lower rates of followup were observed among mothers with low levels of education. Of mothers who had a hearing impaired infant with a neonatal intensive care stay, more than two-thirds of ninth-grade educated mothers failed to return their children for scheduled follow-up appointments, compared to one-third of college-educated mothers who failed to do so.¹⁶

Preventability

Although the exact causes of newborn hearing loss are unknown, population studies and surveillance efforts have resulted in the publication of position statements by the Joint Committee on Infant Hearing in 2000 and 2007 on risk factors associated with infant and childhood hearing loss. These risk factors include family history of permanent childhood hearing loss, selected postnatal or in utero infections, head trauma, syndromes associated with progressive hearing loss, and certain neurodegenerative disorders.^{17,18} See Appendix A for a complete list of risk factors.

Large population studies have approximated that half of newborn hearing loss is hereditary. An estimated 30% of hereditary cases can be attributed to a specific syndrome.¹⁹ Six hundred syndromes and approximately 125 genes have been identified as being associated with hearing loss.¹⁸ Two mitochondrial variants, A1555G and A7445C have been linked to the nonsyndromic cases attributable to genetic factors.¹⁹

The prevention of a health outcome may occur through primary, secondary, or tertiary prevention initiatives. All three types of prevention can be applied to newborn hearing loss. Primary prevention stops the disease or health outcome from occurring by eliminating the exposure. For example, certain bacterial and viral postnatal or in utero infections have been proven to be risk factors for newborn hearing loss (Appendix A). By removing exposure to these pathogens, a mother can reduce the risk that her child will develop hearing loss.

Screening for newborn hearing loss before hospital discharge serves as a form of secondary prevention. Secondary prevention activities reduce the morbidity associated with a health outcome. Early detection of hearing loss has been shown to reduce long-term social, emotional and learning deficits.

Tertiary prevention strategies are designed to reduce the limitations of disability from a given health outcome.²⁰ Although a newborn hearing loss surveillance system does not directly manage the medical care of children with hearing loss and provide services to families, a system such as VEHDIP does have the capability to connect infants and their families to assistive technologies, early intervention services, parent support networks, and other agencies. In 2006, Virginia's Hearing Aid Loan Bank

loaned 83 aids and 12 FM systems to 52 children. Educational, medical, and social resources are essential in improving the lifetime outcomes of an individual with newborn hearing loss. Additionally, VEHDIP is able to identify gaps and barriers to screening, diagnosis and treatment.

Potential Clinical Course in Absence of Intervention

A child with an undetected or untreated hearing loss may suffer learning, language, or social defects. In the absence of universal newborn hearing screening, the average age at which a child is diagnosed with hearing loss is 2 to 3 years of age.³

Irrespective of its severity, undetected hearing loss can greatly inhibit educational functioning. Northern and Downs²¹ found that for every 10 dB of hearing loss over 25 dB, an educational delay of one year can occur. These delays can be associated with language, learning and/or speech development.²² Delays begin in infancy and translate to substantial consequences throughout life. National studies from the 1980s and 1990s found that on average, the language and academic attainment of fourth-grade students with normal hearing exceeded that of high school graduates who were deaf.^{23,24}

Yoshinaga-Itano and colleagues²⁵ observed that children with hearing loss who were identified by 6 months of age performed better on tests of language skills than children identified after 6 months, across all test ages, modes of communication, degrees of hearing loss, and levels of socioeconomic status. These differences remained, even among infants who varied by gender, race/ethnicity, and the presence or absence of comorbid disabilities. In fact, earlier-identified children had a mean language quotient that was almost a full standard deviation higher than later-identified children. This difference amounts to a disparity analogous to delays of 2 years or more. In a previous study, Yoshinaga-Itano²⁶ found that individuals identified with hearing loss before 6 months of age who received intervention basically had normal language at 3 years of age, while 2- to 4-year delays in language were observed in later-identified children. The evidence for the importance of age of initiation of intervention is supported by Moeller²⁷, who concluded that in a cohort of children with hearing loss,

“the age of initiation of intervention predicted 55.5% of the variance in language outcome.”

Early-identified children develop vocabulary and speech more quickly and have more words in their expressive vocabulary, more consonants, phonetic blends, and better speech intelligibility than children identified later.²⁸ However, it is important to note that language development predicts speech intelligibility; it acts as the intermediary between early identification/intervention and development of speech.²⁹

Early identification/intervention also improves the social and emotional development of a child with hearing loss. Children identified early scored higher on personal-social skill indicators on the Minnesota Child Development Inventory than later-identified children.²⁵ Pressman³⁰ found self-development indicators such as self-description/evaluation and self-recognition also were higher in early-identified children.

Public Interest in Hearing Loss

Newborn hearing loss is an issue that has generated support nationally. The first state in the United States to pass a law creating a universal newborn hearing screening program was Hawaii, which did so in 1990. Currently, 42 states have statutes related to newborn hearing screening. Of these, 26 (62%) require screening of all infants.³¹

Many stakeholder groups in the commonwealth have interest in the early identification and intervention services of children with hearing loss. Physicians and nurses, health insurance representatives, educators, speech pathologists, audiologists, early intervention providers, hearing aid dealers and fitters, hospital administrators, and parents all have a stake in newborn hearing screening. Numerous agencies in the commonwealth are involved in issues related to newborn hearing loss, including the VDH, the Department of the Deaf and Hard-of-Hearing, the Department of Education, the Department of Medical Assistance Services, and the Department of Mental Health, Mental Retardation and Substance Abuse Services. Representatives of these stakeholder groups and agencies compose the VEHDIP Advisory Committee, which meets quarterly to discuss issues related to VEHDIP’s operation, current research on newborn hearing screening, and to provide updates from their agencies. The formation of the Advisory Committee was legislatively mandated by the *Code of Virginia* §32.1-

64.1. Overall, the goal of the Advisory Committee is to advise and assist VDH and VEHDIP on maintaining a complete identification and monitoring system that ensures that children with hearing loss achieve communication and social skills proportionate to their cognitive abilities. The Advisory Committee forms special work groups (or subcommittees), as necessary, to address issues related to identification, linkage, intervention, and funding.

Several national organizations support universal newborn hearing screening and the surveillance of newborn hearing loss. The Joint Committee on Infant Hearing publishes position statements with best-practice guidelines related to early identification and intervention of infants at-risk for or with hearing loss.³² This interdisciplinary group has representation from the American Academy of Pediatrics (AAP), the American Speech-Hearing-Language Association, the American Academy of Audiology, the American Academy of Otolaryngology-Head and Neck Surgery, the Directors of Speech and Hearing Programs in State Health and Welfare Agencies, and the Council on Education for the Deaf. Each chapter of the AAP designates an Early Hearing Detection and Intervention (EHDI) Chapter Champion who is responsible for collaborating with state agencies and pediatric health care providers on EHDI programs and activities, as well as directing and responding to health provider concerns surrounding newborn hearing screening.³³ The Chapter Champion for Virginia is a member of the VEHDIP Advisory Committee.

Newborn hearing loss has been identified as an issue of public health importance in Healthy People (HP) 2010. Goal 28-11 of HP2010 is to “increase the proportion of newborns who are screened for hearing loss by age 1 month, have audiologic evaluation by age 3 months, and are enrolled in appropriate intervention services by age 6 months.”³⁴ The Maternal and Child Health Title V Block Grant also has two indicators that address issues related to newborn hearing screening and diagnosis: (1) Percentage of newborns who have been screened for hearing before hospital discharge; and (2) The percent of newborns who fail the hearing screening and who receive a diagnosis before 3 months of age (formerly: the percent of newborns screened for hearing loss who receive recommended follow-up services, 2002-2005).

PURPOSE AND OPERATION OF VEHDIP

Purpose

The purpose of VEHDIP is to ensure that all infants are screened for hearing loss by 1 month of age; to identify infants with hearing loss by 3 months of age; and to assure that infants with confirmed hearing loss are enrolled in appropriate intervention services, including amplification, if needed, by 6 months of age. The program's mission is to "minimize or eliminate communication disorders resulting from hearing loss."³⁵

Planned Uses of Data

VEHDIP staff members plan to continue to use the surveillance system's data to accomplish several goals:

- Establish the disposition of every occurrent birth in Virginia for each step of the hearing screening process.
- Minimize the number of infants who are lost to followup, and expand referrals to early intervention services (Part C and other).
- Better identify infants and children with late onset or progressive hearing loss.
- Expand the integration and linkage of VEHDIP with other child health programs that identify and serve children with special health care needs.
- Aid in the ongoing evaluation of the system.
- Perform routine tracking and surveillance activities, prevalence studies, and ad hoc data requests.
- Guide and support child and adolescent health programs in Virginia.

Case Definition of Event

The Joint Committee on Infant Hearing recommends that a universal hearing program be able to detect "permanent bilateral or unilateral, sensory or conductive hearing loss, averaging 30 to 40 dB or more in the frequency region important for speech recognition (approximately 500-4000Hz)".¹⁷

In Virginia, hospitals and audiologists are able to use several types of equipment to detect hearing loss. At the hospital, auditory brainstem response (ABR) and

otoacoustic emissions (OAE) are the two screening methodologies that are generally accepted as being most effective. For infants in the neonatal intensive care unit (NICU), it is recommended that they be screened with ABR when they are clinically stable. During an ABR test, sensors are placed on the baby's head and sound is introduced to the ears via small earphones while the baby is sleeping. The stimulation from the sound should generate small electrical currents that a computer can recognize and indicate whether the baby is responding appropriately to the sound. The infant passes with a replicable wave V response threshold less than or equal to 25-20 dB.³⁶

During an OAE test, a small probe is inserted in the baby's ear canal and sound is presented through speakers. In response to external stimuli, the cochlea should produce sound that is recognized by the probe. Transient OAE tests emit sound in the speech frequency range, while distortion product OAE tests (DPOAE) can emit sounds at higher frequencies with more frequency specificity.³⁷

A transient evoked otoacoustic emissions (TEOAE) test used in Virginia has an air conduction click stimulus, which is given at an intensity of 80 ± 3 dB SPL. To pass, three of four frequencies (2400, 3200, 4000, and 5000 Hz) must have reproducibility minimally. In DPOAE tests, a pure tone complex is given as a stimulus at maximum levels <70 dB SPL. To pass, $F2=2000, 3000, 4000, 5000$ Hz, and three of four frequencies must have a distortion product ($2F1-F2$) amplitude ≥ 6 dB than measured noise floor levels. Infants who do not pass the initial screening in one or both ears are referred to an audiologist for follow-up evaluation.

During the follow-up evaluation, OAE is required as the initial retest procedure. If the infant passes, the evaluation is complete and no hearing loss is diagnosed. If the infant does not pass on one or both ears or if the OAE is normal but auditory neuropathy (a form of brainstem dysfunction) is suspected, an ABR is completed. As with the initial screening, ABR involves a threshold click for each ear. Failure to pass the ABR is indicative of hearing loss. Audiologists perform subsequent tests to determine the severity of loss.³⁸

When diagnosing severity of hearing loss, audiologists in Virginia use the Directors of Speech and Hearing Program in State Health and Welfare Agencies'

definitions for mild, moderate, severe, and profound hearing loss, as described previously.

Legal Authority for Data Collection

Of the 42 states nationally that have statutes governing newborn hearing screening, 26 (62%) including Virginia mandate universal screening.³¹ In Virginia, the legal authority for data collection is provided by the *Code of Virginia* §32.1-64.1 (Appendix A). This law states that as of July 1, 2000, all infants in the commonwealth must be given a physiological hearing screening prior to discharge from the hospital after birth. All hospitals with newborn nurseries and all hospitals with neonatal intensive care services must abide by this law. Prior to the passage of this legislation, only 70% of hospital births were screened for hearing loss. Section 32.1-64.1 also requires hospitals to determine the risk status for hearing loss on every newborn, regardless of the results of the hearing screening.

A separate law in the *Code of Virginia* §38.2-3411.4 (Appendix A), mandates that all health insurers, health maintenance organizations, and corporations providing subscription contracts for health care coverage provide coverage for infant hearing screening as well as all necessary audiological examinations, as recommended by the national Joint Committee on Infant Hearing. State health coverage plans for state employees and Medicaid must also follow these requirements. Virginia is 1 of 17 states that offers newborn hearing screening as a covered benefit of health insurance.

Organizational Location

VEHDIP is located within the Virginia Department of Health's Office of Family Health Services (OFHS), Division of Child and Adolescent Health (DCAH), Pediatric Screening and Genetic Services (PSGS). OFHS is responsible for public health issues related to chronic disease prevention and control, injury and violence prevention, women's and infants' health, child and adolescent health, dental health, and community nutrition services. DCAH has several programs under the umbrella of PSGS: Virginia Genetics Program, Virginia Newborn Screening Services, and VEHDIP.

Barriers to Surveillance

There are several types of barriers to consider when conducting surveillance of newborn hearing loss and other types of birth defects including administrative and social barriers. Administrative barriers experienced by VEHDIP are predominantly due to a lack of funding. Despite a legislative mandate, there is no money allocated for newborn hearing screening. Hospitals and audiologists are responsible for obtaining their own equipment, training staff, and reporting screening/evaluation results to VEHDIP. VEHDIP is completely funded by grants.

With additional monetary resources, VEHDIP would be able to hire more staff members, offer more training and education opportunities, and overall, be better able to fulfill its goals and objectives. Recent surveys have identified education and training gaps. A statewide survey of audiologists assessed education needs with respect to screening/evaluation equipment as well as referrals to early intervention services. While few respondents noted that they would like to receive additional training on diagnostic equipment, 8% (n=5) did indicate that they were interested in receiving training on auditory steady-state response audiometry (ASSR), a technology used to assess hearing loss. Forty-one percent of respondents (n=25) agreed or strongly agreed that they need more information on how to refer clients to local early intervention services. A recent parent survey revealed that only 68% of parents agreed or strongly agreed that their child's early intervention provider/program had the knowledge of hearing loss and deafness to serve their child. Parents also may have knowledge gaps pertaining to hearing screening and follow-up practices. An evaluation of loss to followup in Virginia found that a third of parents did not fully comprehend information on hearing screening that they received prior to hospital admission. While 89% of respondents of a telephone survey indicated that they understood what the results of the hearing screening meant, a significant percentage (29%) did not realize that the "do not pass" hearing result indicates the need for further testing.

Because of their sensitive nature, the surveillance of all birth defects including newborn hearing loss involves social barriers. Cultural factors related to language and stigma against disability have been identified as contributing to loss to followup. In Virginia, these cultural barriers have been found to make it difficult for families to

understand what hearing loss is, accept it, and deal with it appropriately.³⁹ Similarly, if physicians or medical professionals do not stress the importance of follow-up care, the surveillance system will be weakened. A “wait and see” approach undermines VEHDIP’s messages stressing timely screening and audiological evaluation. Additionally, some people with hearing loss consider themselves to be culturally Deaf or members of the “Deaf-World”; Deaf persons believe that deafness is not a disability and most prefer to use American Sign Language.⁴⁰ With all families, sensitivity is required when discussing communication options (e.g. American Sign Language and cued speech) as well as amplification technologies (e.g. hearing aids and cochlear implants).

Level of Integration With Other Systems

Through their shared use of the Virginia Infant Screening and Infant Tracking System (VISITS), which is a Web-based tracking and data management system, VEHDIP is linked or integrated with newborn screening services, those at-risk for developmental delay (Part C), and the Virginia Congenital Anomalies Reporting and Education System (VaCARES), which is the state’s birth defects registry. Part C Early Intervention (EI) services are coordinated through the Infant and Toddler Connection of Virginia, and there are at least 500 EI providers statewide. One of the goals of VEHDIP is to ensure that infants diagnosed with hearing loss are enrolled in early intervention services by 6 months of age. The Infant and Toddler Connection of Virginia provides a broad range of supports and services, including audiology, speech/language pathology, sign language and cued language services, assistive technology services and devices, nutrition services, occupational and physical therapy, special instruction, social work services, and psychological services..

VEHDIP is also an advisor and participating partner with the Early Childhood Hearing Outreach Project. This pilot project is funded by the National Center for Hearing Assessment and Management and focuses on hearing screening and followup in the Early Head Start and Migrant Head Start populations. Screening the Head Start population furthers the goals of VEHDIP by identifying children who have not received followup to newborn hearing screening, or who have developed hearing loss after the initial hearing screening.

Another program integrated with VEHDIP is the Virginia Hearing Aid Loan Bank. Digital/programmable hearing aids and FM systems are now available on loan for six months for children with hearing loss aged three years or younger. There are no income restrictions on the loan, which allows children with hearing loss to be promptly fitted with amplification while their families have time to secure funding for permanent devices.

The OFHS DataMart is another information system that has the capacity to be integrated with VEHDIP. The DataMart is a collection of Virginia-specific databases stored in a central location that facilitate data linkage and easy access to raw data. Types of data contained in the DataMart include vital statistics (births, deaths, and fetal deaths), hospital discharge data, and population data. Once VEHDIP data are consistently and reliably imported into DataMart, there is great potential for linkage to other databases such as births, deaths, newborn dried-blood spot screening, and the Special Supplemental Nutrition Program for Women, Infants and Children (WIC). Analyzing linked databases would allow VEHDIP staff to learn more about the population of infants with hearing loss and to identify possible social and demographic factors associated with hearing loss and loss to followup.

Flow Chart

The flow chart describing the operation of VEHDIP can be found in Appendix A. An infant enters the flow chart if one of five events occur: (1) infant is referred after the initial screening; (2) infant misses the initial newborn hearing screening; (3) infant is identified to be at-risk for progressive or delayed hearing loss; (4) infant is transferred out-of-state before the screening is completed, or (5) infant is not screened due to parental refusal. All data are entered into VISITS by hospital personnel or VDH staff, and all reports are generated from VISITS.

Population under surveillance

General population: The Commonwealth of Virginia is in the mid-Atlantic region of the United States and is divided into 35 health districts and 134 localities (city/counties) that encompass 40,767 square miles of land. In 2006, Virginia had

7,642,884 residents, making it the 12th most populous state in the nation.⁴¹ The majority (68.4%) of the population is comprised of non-Hispanic white residents, while 20.0% are non-Hispanic black and 6.3% are Hispanic. Approximately one-fourth (23.6%) of the population is under 18 years of age while 11.6% are 65 years or older. Women represent 50.8% of the population, and women of childbearing age (15-44 years) comprise 21.3% of Virginia's population.

Birth population: In 2006, there were 106,474 live births to Virginia residents. Approximately half (48.7%) of the births were female, 57.5% were non-Hispanic white, 21.6% were non-Hispanic black, and 13.5% were Hispanic. Fewer than one in ten infants (8.5%) were born to a teenage mother.

Infant mortality: In Virginia in 2006, the overall state infant mortality rate was 7.1 deaths per 1000 live births. However, this rate varied dramatically by race/ethnicity. Hispanic infants had the lowest infant mortality rate of 4.1 deaths per 1000 live births, followed by non-Hispanic white infants (5.6/1000). The infant mortality rate for non-Hispanic black infants was more than twice that of non-Hispanic white infants (13.8/1000).

Low birthweight: Disparities by race/ethnicity are also evident when considering low birthweight, defined as a birthweight less than 2500 grams. In 2006, approximately 6% of Hispanic infants were low birthweight, compared to 7.2% of non-Hispanic white infants and 12.8% of non-Hispanic black infants.

Prenatal care: Overall, in 2006, 83.9% of mothers entered prenatal care in their first trimester. Non-Hispanic white mothers received early prenatal care most often (89.4%), while non-Hispanic black mothers (79.3%) and Hispanic mothers (68.9%) received early prenatal care less often. More than one thousand (n=1018) mothers in Virginia in 2006 received no prenatal care. Use of the Kotelchuck Index to assess prenatal care utilization indicated that only 47.8% of mothers in 2006 received adequate prenatal care. Mothers who had a live birth in 2006 had an average of 13 prenatal visits.

Time Period of Data Collection

A universal newborn hearing screening program for the Commonwealth of Virginia was mandated as of July 1, 2000. The capacity for data collection was not fully realized until 2002, when the Hearing Screening / Follow-Up module in VISITS became operational in March of 2002.

Where possible, data presented in this evaluation cover the five most recent years of available data (2002-2006).

What Data Are Collected and How

In general, VEHDIP is a passive surveillance system, which means that cases are reported directly to the health department. However, VEHDIP follow-up protocols do incorporate some active components including notifying parents and primary care providers of the need for followup and tracing to find a medical home for every infant. In an active surveillance system, the health department routinely contacts reporting sources to obtain data. Active surveillance systems are more time-intensive and costly than passive surveillance systems.¹

Like the majority (65%) of states with newborn hearing screening programs,³¹ Virginia requires hospitals to report the results of screening to the state department of health. Within one week of hospital discharge, VDH receives results of hearing screening if infant is referred, is identified to be at-risk for progressive or delayed hearing loss, is transferred out-of-state before the test can be completed, is not screened due to parental refusal, or is missed prior to discharge. Hospitals are also required to identify and report infants with one or more indicators for progressive or delayed-onset hearing loss, regardless of hearing screening results. In addition, each month, hospitals report the total number of infants discharged to home in that month as well as the number of discharged infants who passed the hearing screening and had no risk indicators. This report is to be completed no later than the 15th day of the following month. If an infant who was initially missed or referred is brought back to the hospital for a screening, the results should be reported appropriately as a post-discharge screening. Hospital personnel enter data directly into VISITS.

Annually, on January 1, hospitals report information regarding their hearing screening equipment to VDH via fax or mail. This includes the test procedures used for hearing screening, screening equipment utilized, date/record of equipment calibration, screening protocols, referral criteria, contact information (name, e-mail, telephone number) of program director, and name of advising audiologist. Paper copies of hospital annual reporting forms are kept in secure cabinets at VDH.

Within two weeks of an infant's follow-up screening or diagnostic evaluation, audiologists are required to report these results to VDH via mail or fax machine. The VEHDIP Technical Support Specialist is responsible for entering the results of the diagnostic evaluations into VISITS. Currently, there are approximately 400 audiologists in the state who are licensed by the Virginia Department of Health Professionals.⁴² About one-third of these audiologists serve infants and children. Similar to hospitals, biennially, audiologists who serve infants and children report information regarding their hearing screening equipment to VEHDIP staff via fax or mail. If their equipment meets VEHDIP's standards, they are placed on a list of VEHDIP-approved audiologists. These reporting forms are kept in secure cabinets at VDH. Currently, 50 audiologists are on the approved list for screening and diagnostic evaluation while an additional 35 audiologists are approved for screening only.

The data reported by audiologists are similar to the information reported by hospitals; Appendix B lists the mandatory and optional demographic variables collected by these two data providers.

Hospitals also must report to parents and primary care providers, which helps to reinforce messages about follow-up care. In 2007, there were approximately 1000 licensed pediatricians who belonged to the Virginia chapter of the American Academy of Pediatrics (Jane Davis, e-mail communication, April 2, 2008) and nearly 1700 family practice physicians who belonged to the Virginia Academy of Family Physicians.⁴³ VEHDIP staff members are responsible for infant tracking and followup. Guidelines regarding what indicators to collect from hospitals and audiologists are taken from Joint Committee on Infant Hearing recommendations.

As mentioned previously, newborn hearing screening is mandated for all births in Virginia hospitals with newborn nurseries or with neonatal intensive care services.

Currently, there are 60 hospitals that are required by the mandate to screen newborns prior to discharge. Screening for infant hearing loss is voluntary for Virginia residents born out-of-state or in the District of Columbia. Births that occur at home, birthing centers, or military hospitals in Virginia are also not governed by this law. However, these children are encouraged to get screened by a licensed audiologist at a facility approved by VDH as soon as possible after birth. Three military hospitals in the commonwealth have birthing facilities and report hearing screening results voluntarily.

Data Analysis/Dissemination

Data are managed and analyzed by the VEHDIP Surveillance and Evaluation Coordinator (SEC). Surveillance reports are published annually, distributed to stakeholders and published on the VEHDIP Web site. Key indicators on this report include:

- 1) number of live births in Virginia
- 2) number and percent of infants screened prior to hospital discharge
- 3) number and percent of infants transferred to out-of-state hospitals who were screened
- 4) number and percent of non-hospital births that were screened before 1 month of age
- 5) number and percent of infants receiving audiologic diagnosis
- 6) number and percent of infants with an audiologic diagnosis before 3 months of age
- 7) number and percent of infants diagnosed with a hearing loss referred to early intervention services (Part C and other)
- 8) number and percent of infants diagnosed with a hearing loss who are enrolled in early intervention services (Part C and other) before 6 months of age
- 9) number and percent of diagnosed infants with a medical home
- 10) number and percent of families linked to a family-to-family support system
- 11) number and percent of infants who are lost to followup

The SEC also reports annually to CDC's EHDI Program. Virginia data are compiled with other states' data so CDC can compute regional and national statistics regarding screening, diagnosis, and treatment.

Additional data requests are filled by the SEC on a periodic basis. Most data requests come from members of the Advisory Committee or members of the hearing community. The Hearing Module of VISITS is able to produce several canned reports (Appendix A). Raw data are able to be exported into Excel by searching on a range of birthdates, discharge dates, or screening dates.

VEHDIP surveillance data can be used in several ways. They may be used to make oral presentations on hearing loss, to inform policy, to produce written materials, to conduct research, to provide education or technical assistance, or to inform grant-writing.

How Privacy/Confidentiality Is Assured

VEHDIP is in compliance with the VDH Office of Internal Audit's Information Systems Security Requirements as well as the Health Insurance Portability and Accessibility Act of 1996 (HIPAA). Several laws and standards concerning confidentiality and security govern the hearing module of VISITS. To assure confidentiality, VISITS follows the *Code of Virginia* §§ 2.1-342, 2.1-377-386, 32.1-64.2, 32.1-127.1:03 and 32.1-127.1:04. Reporting and screening requirements are consistent with §32.1-64.1, 12 VAC 5-80 (Appendix A) and Sections 505 and 506 of Title V of the federal Social Security Act. Sections 32.1-64.2 (Appendix A) of the *Code of Virginia* declare that information may not be published unless in a statistical study that removes all identifying information. However, parents of children with identified hearing loss, physicians and early intervention providers may be contacted to provide them with information about available health or educational services and resources.

VISITS follows the Regulations for Administration of the Virginia Hearing Impairment Identification and Monitoring System, 12 VAC 5-80. Additionally, VISITS adheres to VDH Information Technology Resources Management Policies and Procedures, Commonwealth of Virginia ITRM Standard SEC2001-01.1 and Proposed Security and Electronic Signature Standards, (HCFA-0049-P) for HIPAA.

VISITS protects confidentiality via four main mechanisms: firewall, encryption, password protection, and assigned security rights.⁴⁴ The firewall is the first line of defense that protects against unauthorized users accessing this private network. All messages coming or going out of VISITS are screened to meet security criteria. Data are encrypted (or encoded) to prevent unauthorized individuals from viewing or modifying them. Users are given unique usernames and passwords that are protected. Only valid users may access the data. These users are also assigned security rights according to their needs. This limits the level of data for reporting and limits the user's ability to access different types or levels of data. For example, VISITS hospital users are able to create, insert, read, select, update data and run reports only for those patients reported by a user from the same hospital. VISITS administrators, however, are able to create, insert, read, select, update data, run reports and delete data for all hospitals statewide.

Contractors, data users and data recipients are required to sign documentation that acknowledges that these personnel are familiar with information systems security/access and confidentiality policies. Original copies of this documentation are kept on file by DCAH.

Funding Sources

The Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration provided grant funds to VEHDIP from 2001 through 2005. These funds were used to staff several positions, including the VEHDIP Follow-Up Coordinator (FC), SEC, and Technical Support Specialist, and to support collaboration with the Infant and Toddler Connection of Virginia, Virginia's Part C Early Intervention System, and Virginia Department of Education. Additionally, the monies were used to make improvements in VISITS and to support basic program activities including: (1) the design and administration of training and education activities for hospital staff, primary care practitioners, audiologists, and early intervention providers; (2) the establishment of a hearing aid loan bank; (3) the production of quarterly and annual reports; and (4) parent resource materials.

MCHB Title V Block Grant funding is used to support additional staff, database maintenance, development and printing of brochures, office expenses, and in-state travel.

Historically, VISITS has been funded by a variety of sources, including (1) US Department of Health and Human Services, Health Resources and Services Administration, MCHB Title V Block Grant; (2) a 3-year grant awarded by MCHB for the Universal Newborn Health Screening Project; (3) Virginia Department of Mental Health and Mental Retardation Substance Abuse Services—Infant and Toddler Connection of Virginia; and (4) a 3-year birth defects surveillance and prevention grant from the CDC for the Virginia Congenital Anomalies Tracking and Prevention Improvement Project.

The redesign of VISITS (VISITS II) is funded by a 3-year CDC EHDI Tracking, Surveillance and Integration grant (Virginia Child Health Information Systems Integration Project), which began in July 2005. With these grant funds, VEDHIP staff will produce and implement VISITS II as well as use VISITS II surveillance data to guide and support child and adolescent health clinical and programmatic decisions. In addition, VISITS II will be electronically linked to other child health surveillance systems such as Care Connection for Children System Users Network. Care Connection for Children (CCC) is a VDH-sponsored statewide network of regional programs that provides health care services, community support, and resources to children with special health care needs.

An additional grant from CDC funded the CDC Program Evaluation Project. In 2006, contractors from Research Triangle Institute (RTI) International conducted exit surveys and interviews of mothers whose children had been screened for hearing loss. Please refer to Appendix A for a copy of the Executive Summary, which includes conclusions and recommendations. The purpose of this project was to identify barriers and factors that contributed to loss or delay to followup in selected states with universal newborn hearing screening programs.

Personnel Requirements

Presently, 5 full-time employees staff VEHDIP. The Program Director (PD) manages the program and has a variety of responsibilities including oversight for the

grant, supervision of other staff members, dissemination of information, and collaboration with partner agencies and organizations to provide training and education. The FC is responsible for direct tracking and follow-up activities, including contact with parents. In addition, the FC works with other programs like Healthy Start to aid in tracking and follow-up activities, develops and updates parent education materials, and works with the PD to assure linkages to family-to-family support. The VEHDIP Follow-Up Specialist (FS) works closely with the FC to contact families and primary care providers (PCPs) of newborns who are transferred out-of-state, to identify a PCP if the birth hospital does not report one, and to help find address and contact information from other programs for parents whose follow-up letters are returned as “undeliverable.” The SEC’s responsibilities are to assure the collection, availability and analysis of quality data as well as to conduct ongoing program evaluation including survey development, implementation, and analysis. In addition, the SEC fills internal and external requests and submits reports to CDC and data providers. Lastly, a Technical Support Specialist is responsible for entering follow-up report data, monitoring data for accuracy, producing and sending letters to parents and PCPs, as well as providing database support to VISITS users statewide.

If additional funds were available, VEHDIP staff members expressed the desire to add staff members to the program. Specifically, an additional staff member who could focus on parent support and issues surrounding parents of infants with hearing loss would be an asset to the program.

Other Resources

In addition to personnel, VEHDIP utilizes several other types of resources in its daily activities. These resources include maintenance of VISITS, rent, computer operating services, phone, funds to develop and distribute brochures, educational materials, and surveys, travel to trainings and conferences, and miscellaneous office supplies.

VEHDIP also funds two additional programs: (1) Guide by Your Side, a program that provides parent-to-parent support to families of children who have been diagnosed

as deaf or hard of hearing; and (2) the Hearing Aid Loan Bank, which has been mentioned previously.

PERFORMANCE OF THE SURVEILLANCE SYSTEM

Data Usefulness

Useful surveillance data may have several functions. They may be able to: (1) detect a health outcome in a timely way to permit accurate diagnosis, prevention, or treatment; (2) provide estimates of morbidity or mortality, including identification of risk factors; (3) detect trends; (4) assess the effect of prevention programs; (5) contribute to performance measures, including those used in needs assessments; or (6) lead to improved clinical, behavioral, social, policy, environmental, or public health practices.

To evaluate the usefulness of VEHDIP data and to describe the program's system attributes, VEHDIP's Advisory Committee and staff members were surveyed. Fifteen of 39 individuals on the Advisory Committee or staff members of VEHDIP (38.5%) responded to the web-based questionnaire, which was administered via SurveyMonkey between January 2008 and February 2008 (Appendix A). The survey participants had varying amounts of experience serving on the Advisory Committee or working with VEHDIP, ranging from one month to more than 5 years. Multiple agencies were represented by the respondents, including VDH, other state agencies, physicians, audiologists, and other partner organizations.

The overwhelming majority of survey respondents (93%) indicated that they have used VEHDIP data in some capacity. Seventy-three percent of all participants made oral presentations using the data, while 47% used the data to inform policy and one-third used data to produce written materials such as reports or newsletters. Three individuals (20%) expressed that they used data to conduct scientific research such as writing an article or conference abstract. Other uses of the data included reporting to other agencies, providing educational and technical assistance, and grant writing.

Annually, VEHDIP contributes data to two Title V Block Grant indicators, which are used to compare Virginia to all other states and assess performance towards the goals set by the states. These indicators are National Performance Measure 12 (percentage of newborns who have been screened for hearing before hospital discharge) and State Performance Measure 3 (percent of newborns who fail the hospital screening and who receive a diagnosis before 3 months of age).

VEHDIP data are also used to inform the major performance measures common to all early hearing detection and intervention programs: (1) percentage of infants screened for hearing loss prior to 1 month of age (recommended benchmark >95%); (2) percentage of infants with an audiologic diagnosis before 3 months of age (recommended benchmark=90%); and (3) percentage of infants diagnosed with a hearing loss who are enrolled in an early intervention program before 6 months of age (recommended benchmark=90%).¹⁸

DESCRIPTION OF SYSTEM ATTRIBUTES

Nine attributes are key to the operation of a surveillance system: simplicity; flexibility; data quality; acceptability; sensitivity; predictive value positive; representativeness; timeliness; and stability. How these attributes function, either individually or in combination with others, reflects how well or poorly a system is able to carry out its mission.

These surveillance attributes were evaluated using a variety of means including analysis of VISITS data, informal interviews with program staff, review of available documentation, a survey of current Advisory Committee members and VEHDIP staff, and a statewide survey of audiologists who serve infants and children under the age of 3. One hundred forty-seven audiologists were mailed a questionnaire about their capacity to diagnose hearing loss in children age birth to 3 years, their knowledge of VEHDIP, their reporting protocols, barriers to followup and existing links between their office and early intervention services. The survey was also available online via SurveyGizmo. In all, 70 facilities responded, yielding a 47.6% response rate (Appendix A). A parent satisfaction survey and a prior evaluation on loss to followup conducted by RTI International also informed the description of VEHDIP's attributes (Appendix A).

Simplicity

A surveillance system's simplicity refers to how complicated its structure is and how easy it is to operate. Some elements of VEHDIP have helped to make it a simpler system, but currently, the system is still complex. As mentioned previously, VEHDIP is a passive surveillance system, which means that it relies upon other sources to provide data rather than directly collecting data itself. However, VEHDIP's follow-up protocols do incorporate some active components including notifying parents and primary care providers of the need for followup and tracing to find a medical home for every infant. In general, passive surveillance systems are simpler to operate than active systems.

One component of VEHDIP that contributes to its complexity is the amount of followup necessary to update data. Loss to followup is of major concern to hearing loss surveillance systems because it reduces the system's ability to accurately quantify and describe hearing loss. VEHDIP employs a full-time FC to address issues related to loss

to followup; in addition, the FS updates contact information and connects infants to a medical home. Getting accurate contact information is a challenge for VEHDIP and accordingly, time and resources are spent on followup.

An additional layer of complexity surrounds the definition of hearing loss and the number of variables required to adequately characterize hearing loss. At least two tests are required to diagnose a hearing loss (the initial screening and an audiologic evaluation), but more tests may be required if the results are unclear/inconclusive or if the baby is fussy. Sixty-three percent of parent satisfaction survey respondents indicated that they needed to take their child to an outpatient retesting site two or more times before all testing was completed. Hearing loss ranges in type, location, and severity, which are all important data elements to collect when performing surveillance. Hearing results may differ between the most recent screening and previous screenings. Also, hospitals and audiologists may use different equipment to screen or evaluate their patients. It is important to collect this information, as types of equipment range in their sensitivity.

Like hospitals, audiologists report directly to VEHDIP, but because they mail/fax their results, an additional layer of complexity is added to the surveillance system as a VEHDIP staff member must then enter the data into VISITS.

Sixty-four percent of audiologists who responded to the audiologist survey indicated that it would be very helpful and 34% indicated that it would be somewhat helpful to report results electronically using VISITS. If given the choice to report via VISITS or by the current reporting format, 71% noted that they would prefer to report via VISITS. If audiologists reported to VISITS as well, the simplicity of the system would increase as a result of making data entry more streamlined.

The method of collecting data, including number and types of reporting sources and time spent collecting data contributes to the simplicity of the surveillance system. As mentioned before, audiologists and hospitals report their data in different ways. However, the data collection is not very time-consuming; the mean time necessary to perform newborn hearing screening is less than 10 minutes.⁹

In general, audiologists who responded to the survey indicated that it was easy and unburdensome to report hearing loss test results to VEHDIP. Eighty-seven percent

noted that they agreed or strongly agreed that it is easy to report test results, and a majority (63%) disagreed or strongly disagreed that reporting test results poses a burden on their time.

On one hand, the design of VISITS has helped to make surveillance of hearing loss in Virginia simpler by streamlining data entry and collection procedures. Hospitals are all able to access VISITS thereby reporting results to one central agency (VDH). Multiple users can access the system at the same time, which reduces the amount of time collecting, entering, and managing data.

On the other hand, VISITS complicates VEHDIP. VISITS was not well-designed for data analysis and dissemination. The ability to query the data is very limited; there are only a few variables on which a data analyst is able to search. It is very difficult, for example, to find children based on name only; a date of birth or range of birth dates is used most often. VISITS users are also constrained by the number of reports available in the interface (Appendix A). Since money and efforts are being focused on the redesigned system, no additional reports are able to be created in VISITS nor are all of the currently available reports functional. Further complicating the analysis and dissemination of data is the fact that VISITS does not have a comprehensive data dictionary and there are no standard analytic protocols or guidelines for the SEC to use when preparing annual reports. This increases the amount of time necessary to prepare data for dissemination and makes it very difficult to reproduce results, thus reducing their reliability.

To address some of the difficulties with VISITS, the Office of Information Management, which is within VDH, and DCAH (including VEHDIP staff) have spent several years revising the system. The length of time necessary to create VISITS II and, ultimately, to implement and train staff members on its use is indicative of its complexity. With the original design of VISITS, efforts were focused on making data collection and entry simple; while there is still work to be done in VISITS to make the interface more user-friendly, the complexity surrounding data analysis and management should be addressed by VISITS II. Although integration with other data sources like VaCARES and birth data will make VISITS more complex, VISITS II should focus on

facilitating these data linkages, as they will improve the quality and usefulness of VEHDIP's surveillance data.

Flexibility

The attribute flexibility refers to the surveillance system's ability to adapt to changing information needs or operating conditions, with little added time, personnel, or funds.

One example of VEHDIP's flexibility was in its ability to make its materials more accessible to non-English speakers. To better accommodate Virginia's diverse population, forms, brochures, and training materials have been translated into other languages. In July of 2004, the brochure "Virginia's Newborn Hearing Screening Program—Helps You Know If Your Baby Can Hear" became available in Mandarin Chinese, Farsi, Korean, Urdu, and Vietnamese. Additionally, the Parent Resource Guide is available in Spanish while the parent letters are available in 6 languages other than English (Farsi, Korean, Mandarin Chinese, Spanish, Urdu, and Vietnamese).

VEHDIP has established two programs in response to needs voiced by parents and program stakeholders. The Hearing Aid Loan Bank was created in 2004 to provide hearing aids at no-cost to families until more permanent aids can be obtained through insurance or other means. The Guide By Your Side (GBYS) program was created in response to the needs of parents of children with hearing loss. Parents remarked that there was a lack of parent-to-parent support for families of children recently diagnosed with hearing loss. This program was adopted from a national model called Hands & Voices.

In 2007, the Joint Committee on Infant Hearing published a position statement on newborn hearing screening that replaced their recommendations from 2000. See Appendix A for the complete list of risk factors for hearing loss in children. VEHDIP's ability to adjust to and implement these recommendations speaks to the system's flexibility. A subcommittee of the VEHDIP Advisory Committee has been established to discuss the changes and how VEHDIP can address them via amended protocols or additional trainings.

Flexibility was also assessed through the VEHDIP Advisory Committee survey. Sixty percent of survey respondents agreed or strongly agreed that VEHDIP was able to adapt to changing information needs. However, when compared to other questions that assessed other system attributes, this statement had the highest percentage of participants (20%) who disagreed with this statement.

Data Quality

Data quality is also very important to a surveillance system. This means that data should be complete as well as valid. To assess data quality, stakeholders were surveyed about their perceptions of data quality, percentages of missing/unknown responses were calculated for several key variables, and the degree to which hospitals and audiologists collect relevant demographic information related to follow-up and contact tracing was examined.

VEHDIP Advisory Committee members view VEHDIP data as being of very high quality. Eighty-seven percent of Advisory Committee survey participants agreed or strongly agreed that VEHDIP collects high quality data. This percentage was the highest of all questions that assessed the system's attributes.

Audiologists, one of the major data providers to VEHDIP, were asked via the audiologist survey about perceptions of the quality of their data. Ninety-seven percent of respondents agreed or strongly agreed that the data that they provide to VEHDIP are of high quality.

Hospitals and audiologists collect many demographic data elements that help to characterize the population of infants who are screened for hearing loss, reduce loss to followup, and connect infants to a medical home. These relevant data elements are included in Appendix B. Since hospitals enter their data directly into VISITS, some of the variables can be designated as required fields, thus increasing their data quality. None of the variables on the audiologist reporting form is mandatory. Some of the data elements are collected by only one source. Audiologists do not collect racial or ethnic information nor do they collect the address, city, or state of the child's primary care provider. However, audiologists do collect the PCP's phone number, which hospitals do not. The audiologist form is somewhat ambiguous with respect to the name and

address of the primary contact. There is a line for address, city/state/zip, and phone number, but it is not immediately clear if this pertains to the infant's residence, the mother's residence or the residence of another contact, nor does the form designate who is the primary contact. The primary contact's phone number and the phone number of the infant's PCP are not collected by hospitals; adding this information to the hospital reporting form may help with loss to followup and connection of infants to a medical home.

Missing, unknown, or invalid responses for key variables are a sign of poor data quality. Several variables were selected to assess their data quality. These variables included first name of infant, last name of infant, PCP's name, infant's race, infant's ethnicity, contact's name (used for followup), and birth hospital (Appendix C). The fields with the greatest percentage of valid responses were last name of infant (100%), contact's name (>99%), and birth hospital (>99%). The race field also contained a high percentage of valid responses. PCP's name, which is used to assure that infants have a medical home, was available in 90% of the records over the years 2002-2006. Infant's first name was valid in 88% of the records. Most of the invalid names were related to giving the infant a name of "Baby Boy" or "Baby Girl." The field with the poorest data quality was ethnicity. Only 43% of records contained a valid response; most of the invalid responses were missing. It is important for key variables to be of high quality in order to improve loss to followup, assure that infants have a medical home, and to facilitate data linkage. Drop-down boxes can improve the quality of categorical variables and implementation of more stringent quality control procedures can assure that other variables (like name and ethnicity) be completed in an accurate manner.

Acceptability

The willingness of organizations and individuals to participate in the surveillance system is known as acceptability. Acceptability was assessed by reviewing screening refusal rates and examining stakeholder (Advisory Committee, audiologists, and VEHDIP staff) and national perceptions of VEHDIP.

Although newborn hearing screening is mandated by law, parents may refuse screening for religious or personal reasons. With an acceptable surveillance system, it is reasonable to expect that few parents would refuse screening. Indeed, this has been the case. From 2002 to 2006, less than 0.1% of parents refused hearing screening for their newborns due to religious or other reasons. These results are comparable to other states, most of which also report high parental acceptance of hearing screening. One study of New York State newborn hearing screening found that less than 0.4% of parents refused hearing screening in the hospital.⁴⁵

VEHDIP has received accolades from national organizations for high screening rates and the presence of an established system of followup. From 2001 to 2003, the state received a rating of “Excellent” from the World Council on Hearing Health Deafness Research Foundation, formerly known as the National Campaign for Hearing Health.

Results of the Advisory Committee survey also helped to describe the acceptability of VEHDIP. By virtue of the fact that they are willing to sit on its advisory board and be involved in making decisions about the system’s operation, Advisory Committee members view the program as acceptable. Furthermore, a variety of organizations are willing to serve on the Advisory Committee. Of the dozens of agencies, organizations, or interested parties that have a stake in newborn hearing screening, only a few groups have a vacancy on the Advisory Committee.

The acceptability of the system is influenced by the degree to which members are truly committed to actively working with program staff to address areas that need improvement. One Advisory Committee survey participant noted that despite the fact that VEHDIP has areas for improvement to accomplish its mission, “I look forward to working with this board to make great strides for our deaf and hard-of-hearing infants in the Commonwealth of Virginia.” This sentiment was echoed by another respondent who praised the efforts of the VEHDIP staff to improve the system with respect to identification and followup and stressed the Advisory Committee’s support in this endeavor: “[VEHDIP staff] have been relentless in their attempts to continuously improve the system for identification and follow-up and the Advisory Committee is very

dedicated. We're committed to working toward 100% in both areas [identification and follow-up].”

The acceptability of the system is also influenced by the degree to which Advisory Committee members view the system as being able to accomplish its goals and objectives. The Advisory Committee survey asked participants to rate the degree to which they believed VEHDIP was able to (1) assure that infants receive an initial hearing screening prior to hospital discharge; (2) connect infants to audiologists in order to provide diagnostic evaluations; (3) connect infants diagnosed with hearing loss to early intervention services; and (4) connect infants to a medical home. Of these program goals, 60% of participants agreed or strongly agreed that VEHDIP was able to accomplish goal 1, two-thirds agreed or strongly agreed that VEHDIP was able to accomplish goal 2, 73% agreed or strongly agreed that VEHDIP was able to accomplish goal 3, but only one-third agreed or strongly agreed that VEHDIP was able to accomplish goal 4.

Results of the audiologist survey suggest that audiologists in the Commonwealth of Virginia also view VEHDIP as an acceptable surveillance system, due to the fact that audiologists see the value in reporting test results to VEHDIP, believe that the information they provide is being kept confidential and private, and agree that VEHDIP provides their facility with helpful information. All of the audiologists surveyed agreed (46%) or strongly agreed (54%) that they see the value in reporting to VEHDIP. Individuals may also be more willing to participate in a system that they view as being confidential and secure. Eighty percent of responding audiologists agreed or strongly agreed that VEHDIP is able to keep audiological test results and data private and confidential. The majority of audiologists who participated in the survey (71%) noted that VEHDIP provides their facility with helpful information. Two measures previously used to assess simplicity also apply to acceptability. If a data provider believes that a system is easy to use and does not pose a burden on his/her time, that provider may be more likely to participate. A majority of audiologists agreed or strongly agreed that reporting test results does not pose a burden on their time (63%) and that it is easy to report to VEHDIP (87%).

The results of the Advisory Committee and audiologist surveys indicate that these stakeholder groups view VEHDIP as acceptable, but the program's acceptability may increase if the Advisory Committee members believe that the program is better able to accomplish its goals, especially its goal to connect infants to a medical home, and if audiologists continue to be able to report to VEHDIP in a timely and easy manner.

Sensitivity

Sensitivity can be defined in two ways. Mathematically, it is the proportion of cases of a disease detected by the surveillance system. Alternatively, it can be defined as the system's ability to monitor changes in number of cases over time.

VEHDIP's sensitivity was calculated by comparing the expected prevalence of newborn hearing loss in Virginia with the number of cases identified by the surveillance system. As mentioned previously, newborn hearing loss affects one to three of every thousand infants born in the United States. With approximately 100,000 live births per year, we would expect VEHDIP to record between 100 and 300 cases of hearing loss per year. From 2002 to 2006 the actual number of cases of hearing loss captured by VEHDIP hovered around the lower estimate, but in general, the number increased with time. In 2002, 109 cases were recorded, followed by 103 in 2003, 122 in 2004, 129 in 2005, and 135 in 2006.

VEHDIP staff have attributed the low sensitivity to "underreporting of unilateral and/or mild hearing loss, accessibility to audiological facilities in rural areas, language barriers, and the disconnect between primary care providers and hospitals."⁴⁶ Data from prior annual reports and the audiologist survey support these hypotheses. Nationally, in 2004, 52% of infants with hearing loss experienced a bilateral loss, 30% experienced a unilateral loss, and 18% were unspecified.³ Comparatively, in Virginia, a higher percentage of hearing loss was bilateral (69%) while only 28% was unilateral. Sixty-one percent of audiologists who responded to the audiologist survey noted that inconvenient travel distance poses a challenge/barrier to followup sometimes, nearly always, or always. Fifty-four percent indicated that lack of transportation to the audiologist is a barrier to followup sometimes, nearly always, or always, and 51%

believed language spoken by families prevents linkage to services sometimes, nearly always, or always.

Predictive Value Positive

Predictive value positive (PVP) is another calculation that speaks to how well the surveillance system is functioning. A correlate to sensitivity and specificity, PVP is the proportion of reported cases that actually has the health outcome under surveillance. In the case of hearing screening, it is the proportion of individuals who are referred for an audiological evaluation who actually have hearing loss.

From 2002 to 2006, 14,216 infants were referred for subsequent audiological evaluation on one or both ears after their initial newborn hearing screening. Of these infants, 11,366 received followup. About 15% (n=1,715) of infants who received followup failed one or more follow-up screens. Of the infants who received followup, 437 received a diagnosis of hearing loss in one or both ears. This equates to a PVP of 3.1% if the denominator is all infants who were referred on their initial hearing screening or 3.8% if the denominator is all infants who were referred on their initial screening and received at least one follow-up visit. These analyses were replicated for left ear and right ear. The PVPs of diagnosis for all infants who received followup on the left ear or right ear were 4.1% and 3.4%, respectively (Appendix B).

False-positive results may contribute to parental anxiety, and lead to unnecessary follow-up tests or intervention. However, despite its low PVP, universal newborn hearing screening is cost-effective in the long term compared to no screening or selective screening in the neonatal intensive care unit.¹⁰

Representativeness

Descriptive epidemiology involves the person, place, and time associated with a health outcome. A representative surveillance system accurately describes the occurrence of an event over time and its distribution in the population in terms of place and person.

To evaluate representativeness, contact addresses of infants with hearing loss and addresses of audiological facilities on the VEHDIP-approved list were geocoded by

the VDH Division of Disease Prevention. Subsequently, the data were loaded into ArcView geographic information software and maps were created to describe the relationship between audiological facility locations and the residential locations of infants with hearing loss who were identified by VEHDIP.

From 2002 to 2006, cases of hearing loss were spread across the state, and were concentrated in urban metropolitan areas, including the areas around Washington, DC (Arlington, Alexandria, Fairfax), Richmond (including Henrico and Chesterfield), and Norfolk/Portsmouth/Virginia Beach. The number of cases per locality during this time period ranged from 0 to 101. A map depicting the distribution of cases by locality and the location of audiological facilities is found in Appendix C.

Audiologists on the VEHDIP-approved list were found throughout the state, but some regions were better represented and, accordingly, residents of these areas required less travel distance to reach the nearest audiological facility. The majority of cases of infants with hearing loss who lived a distance greater than 10 miles from an audiological facility were found in the southcentral (Southside/Crater/Piedmont area) or northcentral parts of the state. A map showing the distance between residence and audiological facility is found in Appendix C.

Timeliness

Timeliness simply denotes the time between onset of an event and the reporting of that event. In the case of newborn hearing screening, timeliness is essential to diagnose and intervene to minimize the effects of hearing loss.

Timeliness was assessed using five mechanisms: (1) stakeholder perception of timeliness, (2) benchmarking to performance indicators, (3) degree to which hospitals and audiologists report to VEHDIP in a timely manner, (4) amount of time necessary to analyze and publish surveillance data, and (5) time between scheduling an outpatient retesting appointment and the actual appointment.

About half (53%) of VEHDIP Advisory Committee survey respondents agreed or strongly agreed that VEHDIP is able to collect data in a timely manner. The Advisory Committee members' perceptions of VEHDIP's surveillance system attributes are important because the committee members are influential stakeholders in newborn

hearing screening in Virginia. If they view VEHDIP's performance negatively, they may be less willing to advocate for changes in funding or legislation.

The Joint Committee on Infant Hearing has published three key indicators that address timeliness of screening, diagnosis, and enrollment in early intervention services and are known as the "1-3-6 Plan." The first goal states that infants should be screened prior to 1 month of age; according to the VEHDIP 2006 Annual Report, 99.3% of infants received a hearing screening prior to 1 month of age.⁴⁶ This exceeds the national benchmark of 95%. The second goal states that all infants who fail the hearing screening should receive a diagnostic evaluation that confirms or rules out hearing loss by 3 months of age. In Virginia in 2006, 68.1% of infants received a diagnostic evaluation prior to 3 months of age, which is less than the national benchmark of 90%. The third goal states that all infants diagnosed with hearing loss should be enrolled in early intervention services before 6 months of age. In 2006, 78.4% of Virginia infants with confirmed hearing loss received early intervention services before 6 months of age. This performance also falls short of the national benchmark (90%).

As mentioned previously, the Maternal and Child Health Title V Block Grant has two indicators that address timeliness. Prior to 2006, State Performance Measure 3 was "the percent of newborns screened for hearing loss who receive recommended follow-up services." In 2006, this was changed to "the percent of newborns who fail the hearing screening and who receive a diagnosis before 3 months of age." In general, from 2002-2005, this indicator increased over time; however, in 2006, Virginia's performance dropped, in part because of a change in the measure's definition (Appendix C). The second indicator, National Performance Measure 12, is "the percentage of newborns who have been screened for hearing before hospital discharge." During 2002-2006, Virginia came very close to meeting the performance objective, which is 100% (Appendix C).

Hospital and audiologist protocols address timeliness. Hospitals are required to enter screening results into VISITS within 7 days of hospital discharge, while audiologists are responsible for reporting results of evaluations to VEHDIP within 14 days of the screening/evaluation. From 2002-2006, the average number of days between hospital discharge and entry into VISITS decreased. However, the percentage

of hospitals who were in compliance with the 7 day requirement remained low. In 2002, 15% of hospitals were in compliance and by 2006, 40% of hospitals were reporting screening results via VISITS within 7 days (Appendix C). From 2002-2005, there was little improvement in the timeliness of audiologists' reporting. The percentage of audiologists who reported within 14 days ranged from 40% to 43% until 2006, when it increased to 49% (Appendix C).

The results of the audiologist survey also addressed timeliness. Ninety-seven percent of the responding audiologists agreed or strongly agreed that they were able to report results of their evaluations in a timely fashion (within 2 weeks of the visit). This was inconsistent with the results from the timeliness assessment using VISITS data, which found that less than 50% of audiologists reported to VEHDIP within 14 days.

Some but not all of VEHDIP's data are collected electronically. Electronic data collection has strengths and weaknesses. On one hand, the use of VISITS has the potential to improve the timeliness of data collection from the hospitals compared to the audiologists who fax or mail their results. However, the structure of VISITS inhibits the timely release of surveillance data.

Previously, 9 months elapsed between the end of a calendar year and the publication of a report summarizing the previous year's data. Beginning in 2007, the SEC will wait a full calendar year to analyze data, so 2007 data will be analyzed in January 2009. This change was made to allow for the collection of more complete follow-up data and to coincide with the creation of the CDC annual report, which also follows this timeline.

Parents of children with hearing loss who responded to the parent satisfaction survey were questioned about the length of time between the first attempt to make an outpatient retesting appointment and the actual appointment. Thirty percent of respondents (n=26) indicated that it took between 2 weeks and 1 month to schedule and go to an outpatient retesting appointment. An additional 20% (n=17) said that it took 1 to 2 months, and 16% (n=14) indicated that it took more than 2 months. Delays in accessing follow-up visits affect the attainment of the 1-3-6 goals. Evaluators from RTI suggested ways to address the timeliness of follow-up appointments, including "scheduling follow-up appointments prior to discharge, making reminder calls and

sending reminder letters for high-risk families who face various barriers to accessing health care.”³⁹

Stability

Stability is the final key attribute to a surveillance system. With stability, a system is able to be reliable and available, even in the presence of financial, political, technical, or other forms of stress. VEHDIP’s stability was assessed via the Advisory Committee survey, as well as an examination of the number of system outages, amount of staff turnover, and steadiness of funding.

Advisory Committee survey participants were asked about the degree to which they believed VEHDIP was able to collect, manage, and provide data on a regular basis. The majority of respondents agreed or strongly agreed with these statements, ranging from 73% (manage data) to 80% (collect and provide data).

A stable surveillance system is also able to be accessed on a regular basis, without the limitations of power outages, system upgrades, or technical difficulties. Beginning in April of 2006, access to VISITS was available 24 hours a day and 7 days a week. Prior to that, the system was shut down over the weekend for repairs on a regular basis. Since VISITS became available 24/7, there have been less than 14 hours of outage, at which time system administrators have applied security patches or performed system maintenance.

Staffing and funding are two additional potential sources of instability. From VEHDIP’s inception until July 2007, there was no turnover in the Program Manager position, allowing for the development of a great deal of institutional memory and the creation of strong relationships with stakeholders. Although a new Program Manager was unable to be hired until January 2008, VEHDIP functioned well in the interim; other VEHDIP staff members and the Director of Pediatric and Genetic Services stepped up to fill this role.

Although funding has not steadily come from one source, VEHDIP has been able to compose competitive grant applications and obtain money from a variety of sources including the Maternal Child Health Bureau of the Health Resources and Services Administration, the Virginia Department of Mental Health and Mental Retardation

Substance Abuse Services—Infant and Toddler Connection of Virginia, and CDC. In the event that these funding sources were unavailable, VEHDIP would most likely be supported by OFHS through the use of Title V Block Grant funds.

To enhance the reliability and availability of VEHDIP data and improve data collection, management, and analysis, the current VISITS system is being redesigned. The primary aims of VISITS II are to minimize the number of infants who are lost to followup; expand referrals of children with special health care needs to appropriate early intervention or care coordination services; enhance the mechanism for identifying infants and children with late onset or progressive hearing loss; improve birth and death certificate linkage methodology to ensure unduplicated individually identifiable data; comply with data requests; expand linkage and integration with other surveillance systems; improve efficiency, security, and cost-effectiveness; and assure the data are of high-quality.

Several quality assurance and quality control mechanisms will be built into the redesign of the current system. The technical enhancements to VISITS began in 2005 and plan to be fully implemented no later than June 2009. New quality assurance mechanisms for VISITS II include built-in range checks for numerical variables to promote accurate abstraction and data entry, automated calculations and conversions for appropriate variables (e.g. birthweight), use of coded data, drop-down boxes, and standard variable definitions to facilitate linkage with other data sets. Linkages to birth and death files as well as other child health surveillance systems will be made simpler with standard variable definitions and coding mechanisms. Planned quality control mechanisms include logic edits, creation of date-posting fields, development of transaction logs, creation of queries and reports that are specified by data users, development of methods to remove duplicate cases, creation of queries to identify problem situations, improvement of case ascertainment and program operation efficiency, and formation of methods to improve timeliness.

CONCLUSIONS

The purposes of this evaluation were to assess the degree to which VEHDIP is meeting its objectives, serving a useful public health function, and operating effectively and efficiently. VEHDIP conducts statewide surveillance of newborn hearing loss while serving its goals, which are to ensure that all infants are screened for hearing loss by 1 month of age; to identify infants with newborn hearing loss by 3 months of age; and to assure that infants with confirmed hearing loss are enrolled in appropriate intervention services, including amplification, if needed, by 6 months of age.

VEHDIP is performing best at assuring that all infants receive an initial hearing screening. The secondary and tertiary goals are inhibited by loss to follow-up, which is a major obstacle that VEHDIP staff members are actively trying to improve. Past evaluation efforts have been focused on identifying some of the barriers to follow-up; staff members are working to implement recommendations from those evaluations.

National- and state-based research publications have provided evidence that newborn hearing screening serves a useful public health function. In the absence of screening, the average age at which a child is diagnosed with hearing loss is between 2 and 3 years of age. Undetected hearing loss impairs educational, social, and emotional functioning from infancy into adulthood. Early intervention has been found to improve these types of functioning.

The major barrier to the effective and efficient operation of VEHDIP is the design of VISITS and its inability to facilitate accurate and reliable data analysis. VISITS II is projected to be implemented by June 2009, and soon afterward, the SEC will be able to readily use the surveillance data to produce routine reports as well as perform more sophisticated analyses such as geographic analyses and data linkage. Enhancements and new features of VISITS II will help to address some limitations of the current system, including improved reporting and tracking functions, integration with the electronic birth certificate, automatic/semi-automatic referrals to CCC, as well as better documentation for decision-making. VEHDIP's staff members are supported by a dedicated Advisory Committee and are well-poised to manage program and surveillance needs in order to make VEHDIP and newborn hearing loss surveillance stronger in Virginia.

RECOMMENDATIONS

- Construct better documentation for use in analytic decision-making:
 - Compose complete data dictionary for VISITS II.
 - Assure outcomes are defined consistently (i.e. what is a hearing loss?).
 - Document exclusion criteria for analyses to enhance reproducibility, such as restricting analyses to Virginia residents, Virginia hospitals, or infants who were screened for hearing loss prior to hospital discharge.

- Continue to update other relevant documentation in case of staff turnover.

- Continue to give hospitals feedback on their reporting time and consider benchmarking hospitals against other hospitals in their network or region.

- Consider providing reporting time feedback to audiologists or extending audiologists access to VISITS to improve timeliness.

- Develop strategies to address education and training gaps identified by the audiologist survey and RTI International’s evaluation of loss to followup.

- Increase data usefulness by enhancing links to other data sets and continuing to partner with other divisions and agencies to better describe the population of infants/children with hearing loss. The grant examining the impact of hearing loss and comorbidity on Virginia’s children and families is an example of such a partnership.

- Improve collection of early intervention and other outcome data including school outcomes, communication choices and amplification technologies such as hearing aid fitting and cochlear implants.

- Enhance links to early intervention (Part C and other) and CCC to aid referrals to services.

- Continue to improve loss to followup and connection of infants to a medical home.
- Increase audiologist coverage in southcentral and northcentral Virginia.

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APPENDIX A: Documents

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Relevant *Code of Virginia* Legislation

§32.1-64.1. Virginia Hearing Impairment Identification and Monitoring System

A. In order to identify hearing loss at the earliest possible age among newborns and to provide early intervention for all infants so identified as having hearing impairment, the Commissioner shall establish and maintain the Virginia Hearing Impairment Identification and Monitoring System. This system shall be for the purpose of identifying and monitoring infants with hearing impairment to ensure that such infants receive appropriate early intervention through treatment, therapy, training and education.

B. The Virginia Hearing Impairment Identification and Monitoring System shall be initiated in all hospitals with neonatal intensive care services, in all hospitals in the Commonwealth having newborn nurseries, and in other birthing places or centers in the Commonwealth having newborn nurseries.

C. In all hospitals with neonatal intensive care services, the chief medical officer of such hospitals or his designee shall identify infants at risk of hearing impairment using criteria established by the Board. Beginning on July 1, 1999, all infants shall be given a hearing screening test, regardless of whether or not the infant is at risk of hearing impairment, by the chief medical officer or his designee using methodology approved by the Board. The test shall take place before the infant is discharged from the hospital to the care of the parent or guardian, or as the Board may by regulation provide. In all other hospitals and other birthing places or centers, the chief medical officer or his designee or the attending practitioner shall identify infants at risk of hearing impairment using criteria established by the Board.

D. Beginning on July 1, 2000, the Board shall provide by regulation for the giving of hearing screening tests for all infants born in all hospitals. The Board's regulations shall establish when the testing shall be offered and performed and procedures for reporting. An infant whose hearing screening indicates the need for a diagnostic audiological examination shall be offered such examination at a center approved by the Board of Health. As a condition of such approval, such centers shall maintain suitable audiological support and medical and educational referral practices.

E. The Commissioner shall appoint an advisory committee to assist in the design, implementation, and revision of this identification and monitoring system. The advisory committee shall meet at least four times per year. A chairman shall be elected annually by the advisory committee. The Department of Health shall provide support services to the advisory committee. The advisory committee shall consist of representatives from relevant groups including, but not limited to, the health insurance industry; physicians, including at least one pediatrician or family practitioner, one otolaryngologist, and one neonatologist; nurses representing newborn nurseries; 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, including the Department of Medical Assistance Services, the Department of Education, and the Department for the Deaf and Hard-of-Hearing. The Department of Education, the Department for the Deaf and Hard-of-Hearing, and the Department of Mental Health, Mental Retardation and Substance Abuse Services shall cooperate with the Commissioner and the Board in implementing this system.

F. With the assistance of the advisory committee, the Board shall promulgate such rules and regulations as may be necessary to implement this identification and monitoring system. These rules and regulations shall include criteria, including current screening methodology, for the identification of infants (i) with hearing impairment and (ii) at risk of hearing impairment and shall include the scope of the information to be reported, reporting forms, screening protocols, appropriate mechanisms for follow-up, relationships between the identification and monitoring system and other state agency programs or activities and mechanisms for review and evaluation of the activities of the system. The identification and monitoring system shall collect the name, address, sex, race, and any other information determined to be pertinent by the Board, regarding infants determined to be at risk of hearing impairment or to have hearing loss.

G. In addition, the Board's regulations shall provide that any person making a determination that an infant (i) is at risk for hearing impairment, (ii) has failed to pass a hearing screening, or (iii) was not successfully tested shall notify the parent or guardian of the infant, the infant's primary care practitioner, and the Commissioner.

H. No testing required to be performed or offered by this section shall be performed if the parents of the infant object to the test based on their bona fide religious convictions.

(1986, c. 419; 1998, cc. 505, 506, 513; 2004, c. 855.)

§32.1-64.2. Confidentiality of records; publication; Commissioner required to contact parents, physicians, and relevant local early intervention program.

The Commissioner and all other persons to whom data is submitted pursuant to § 32.1-64.1 shall keep such information confidential. No publication of information shall be made except in the form of statistical or other studies which do not identify individuals. However, the Commissioner shall contact the parents of children identified with hearing impairment or at risk of hearing impairment, their physicians and the relevant local early intervention program to provide them with information about available public and private health care and educational resources including any hearing impairment clinics.

(1986, c. 419; 1998, cc. 505, 506, 513.)

§38.2-3411.4. Coverage for infant hearing screening and related diagnostics.

A. Notwithstanding the provisions of §38.2-3419 each insurer proposing to issue individual or group accident and sickness insurance policies providing hospital, medical and surgical, or major medical coverage on an expense-incurred basis; each corporation providing individual or group accident and sickness subscription contracts; and each health maintenance organization providing a health care plan for health care services shall provide coverage for infant hearing screenings and all necessary audiological examinations provided pursuant to §32.1-64.1 and as prescribed herein for newborn children under each such policy, contract or plan delivered, issued for delivery or renewed in this Commonwealth on and after July 1, 2001.

B. For purposes of this section, such coverage shall provide coverage for infant hearing screenings and all necessary audiological examinations provided pursuant to §32.1-64.1 using any technology approved by the United States Food and Drug Administration, and as recommended by the national Joint Committee on Infant Hearing in its most current position statement addressing early hearing detection and intervention programs. Such coverage shall include benefits for any follow-up audiological examinations as recommended by a physician or audiologist and performed by a licensed audiologist to confirm the existence or absence of hearing loss.

C. Nothing contained in this section shall abrogate any obligation to provide coverage for hearing screening tests or any other hearing screening test or audiological diagnostic procedure pursuant to this section or any other law or regulation of the Commonwealth or of the United States or under the terms or provisions of any policy or plan issued, renewed, reissued or extended in the Commonwealth.

D. The provisions of this section shall not apply to short-term travel, accident only, limited or specified disease policies, or contracts designed for issuance to persons eligible for coverage under Title XVIII of the Social Security Act, known as Medicare, or any other similar coverage under state or federal governmental plans, or to short-term nonrenewable policies of not more than six months' duration.

(2001, c. 663.)

Virginia Administrative Code Chapter 80 Regulations for Administration of the Virginia Hearing Impairment Identification and Monitoring System

12VAC5-80-10. Definitions.

The following words and terms when used in this chapter shall have the following meanings, unless the context clearly indicates otherwise:

"At risk" means considered to be in a status with a significant probability of having or developing hearing loss as a result of the presence of one or more factors identified or manifested at birth.

"Child" means any person from birth to age 18 years of age.

"Commissioner" means the State Health Commissioner, his duly designated officer, or agent.

"Diagnostic audiological evaluation" means those physiologic and behavioral procedures required to evaluate and diagnose hearing status.

"Discharge" means release from the hospital after birth to the care of the parent.

"Hearing screening" means an objective physiological measure to be completed in order to determine the likelihood of hearing loss.

"Infant" means a child under the age of one year.

"Missed" means that an infant did not have a required hearing screening prior to discharge.

"Neonatal intensive care services" means those services provided by a hospital's newborn services that are designated as both specialty level and subspecialty level as defined in subdivision D 2 of 12VAC5-410-440.

"Parent" means (i) a biological or adoptive parent who has legal custody of a child, including either parent if custody is shared under a joint decree or agreement; (ii) a biological or adoptive parent with whom a child regularly resides; (iii) a person judicially appointed as a legal guardian of a child; or (iv) a person who exercises the rights and responsibilities of legal custody by delegation from a biological or adoptive parent, upon provisional adoption or otherwise by operation of law.

"Primary medical care provider" means the person to whom the infant will go for routine medical care following hospital discharge.

"Risk factor" means a factor known to place an infant at increased risk for being born with or developing a hearing loss, including, but not limited to, any one of the following:

1. Family history of hereditary, childhood sensorineural hearing loss;
2. In utero infection (e.g., cytomegalovirus, rubella, herpes, toxoplasmosis, syphilis);
3. Craniofacial anomalies including those with morphological abnormalities of the pinna and ear canal;
4. Birthweight less than 1500 grams;
5. Hyperbilirubinemia at a serum level requiring exchange transfusion;
6. Bacterial meningitis;
7. Apgar scores of 0 to four at one minute or 0 to six at five minutes;
8. Ototoxic medications, including but not limited to the aminoglycosides, used in multiple courses or in combination with loop diuretics;
9. Mechanical ventilation lasting five days or longer;
10. Stigmata or other findings associated with a syndrome known to include a sensorineural hearing loss, a conductive hearing loss, or both;
11. Neurofibromatosis Type II; and
12. Persistent pulmonary hypertension of the newborn (PPHN).

12VAC5-80-20. Authority for regulations.

Sections 32.1-64.1 and 32.1-64.2 of the Code of Virginia direct the commissioner to establish and maintain a system for the purpose of identifying and monitoring infants with hearing loss and directs the Board of Health to promulgate the regulations necessary for implementation of the system.

12VAC5-80-30. Purpose of chapter.

This chapter is designed to provide consistent guidelines for implementation of this system in order to assure that infants with hearing loss are identified at the earliest possible age and that they receive appropriate, early intervention.

12VAC5-80-40. Administration and application of chapter.

A. This chapter is promulgated to implement the system and amended as necessary by the State Board of Health. The State Health Commissioner or his designee is charged with its administration, and the Virginia Department of Health shall provide the staff necessary for its implementation.

B. This chapter has general application throughout the Commonwealth.

12VAC5-80-50. [Repealed]

12VAC5-80-60 to 12VAC5-80-70. [Reserved]

12VAC5-80-80. Responsibilities of hospitals.

Hospitals with newborn nurseries and hospitals with neonatal intensive care services shall:

1. Prior to discharge after birth, but no later than three months of age, screen the hearing, in both ears, of all infants using objective physiologic measures. The methodology used for hearing screening shall have a false-positive rate and false-negative rate no greater than those recommended by the American Academy of Pediatrics in "Newborn and Infant Hearing Loss: Detection and Intervention" (Pediatrics Vol. 103, No. 2, February 1999). If the error rates exceed these recommendations, the hospital shall examine and modify its hearing screening methodology to reduce its error rates below these maximum rates;
2. If an infant is missed, inform the parent prior to discharge of the need for hearing screening and provide a mechanism by which screening can occur at no additional cost to the family;
3. Prior to discharge, give written information to the parent of each infant that includes purposes and benefits of newborn hearing screening, indicators of hearing loss, procedures used for hearing screening, results of the hearing screening, the recommendations for further testing, and where the testing can be obtained;
4. Give written information to the infant's primary medical care provider that includes procedures used for hearing screening, the limitations of screening procedures, the results of the hearing screening, and the recommendations for further testing;
5. Within one week of discharge, complete the Virginia Department of Health report as required by the board pursuant to §32.1-64.1 F of the Code of Virginia and in a manner devised by the department, which may be electronic, on each infant who does not pass the hearing screening and send it to the Virginia Department of Health;
6. On a monthly basis, send to the Virginia Department of Health a report of the total number of discharges, the total number of infants who passed the newborn hearing screening, the total number who failed, and the total number not tested due to parents' exercise of their rights under §32.1-64.1 H of the Code of Virginia; and
7. Report to the Virginia Department of Health, on a yearly basis, the test procedures used by the newborn hearing screening program, the name of the program director, the

name of the advising audiologist, equipment calibration records, screening protocols, and referral procedures.

12VAC5-80-90. Responsibilities of the Virginia Department of Health.

The Virginia Department of Health shall:

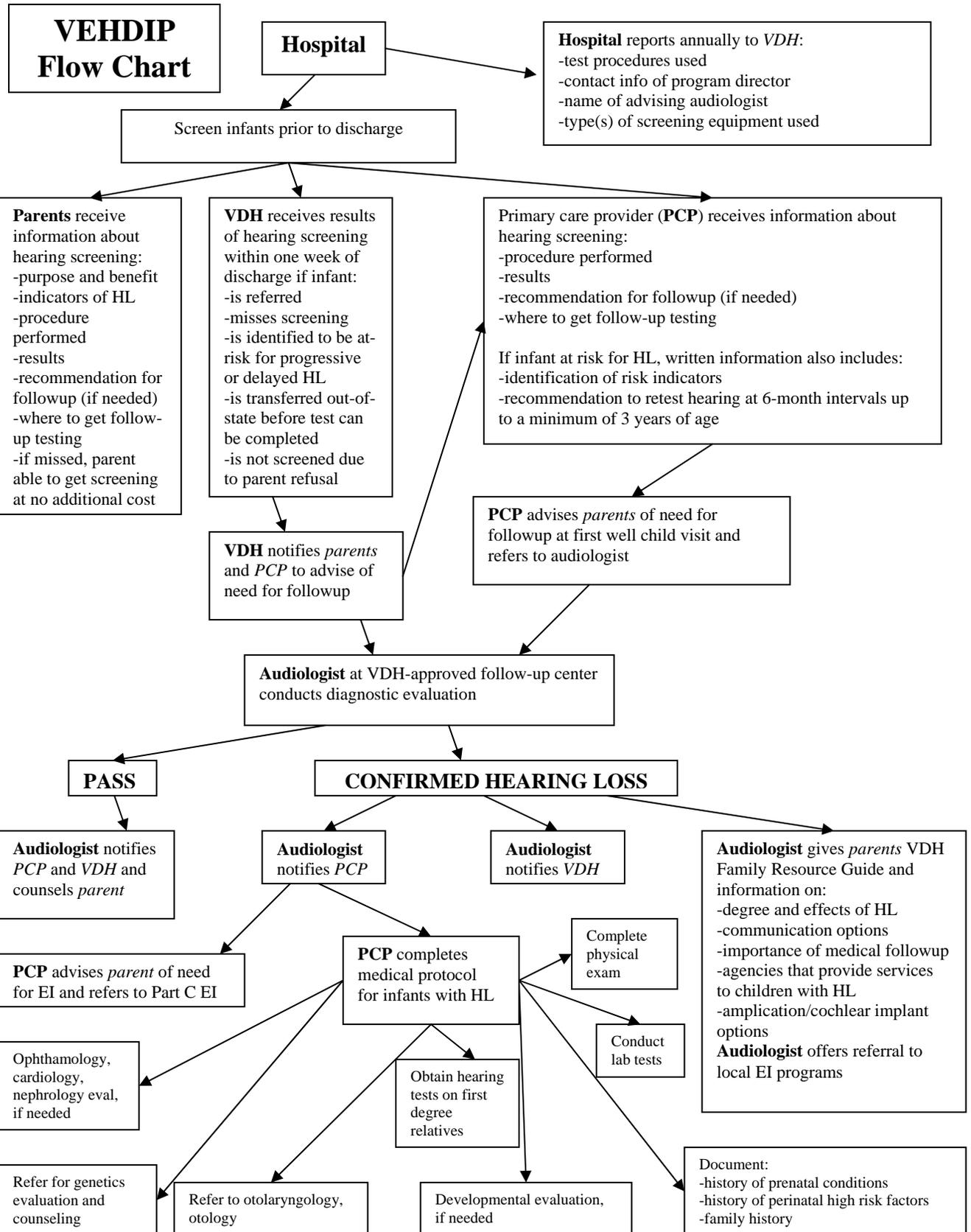
1. Collect, maintain and evaluate hospital newborn hearing screening data in a database;
2. Provide follow-up for all infants reported. Follow-up includes, but is not limited to:
 - a. Communicating with the parent by mail for those infants who failed the hearing screening, those who had one or more risk factors identified and were not screened prior to discharge, those who were not screened, and those who are at risk for progressive hearing loss in order to advise of the need for audiological services as well as to provide information on locating an approved center that provides diagnostic audiological services or a licensed audiologist;
 - b. Receiving results of both the audiological evaluations and the intervention referrals, and adding the information to the database; and
 - c. Communicating with the parent by mail for any child found to have a hearing loss in order to provide information about hearing loss and appropriate resources;
3. Supply the reporting format and written information to hospitals;
4. Provide training and technical assistance on this program to hospitals; and
5. Conduct a review and evaluation of the Virginia Hearing Impairment Identification and Monitoring System, including but not limited to the false-positive rate, false-negative rate, referral rate, follow-up rate, referral mechanisms and effectiveness of tracking, and communicating critical performance data to hospitals, on a yearly basis.

12VAC5-80-95. Responsibilities of persons providing audiological services after discharge.

Persons who provide audiological services and who determine that a child has failed to pass a hearing screening, was not successfully tested, or has a hearing loss shall:

1. Provide the screening or evaluation results to the parent and to the child's primary medical care provider;
2. Send a Virginia Department of Health report including test results, diagnosis, and recommendations to the Virginia Department of Health, in a manner devised by the department, which may be electronic, within two weeks of the visit;

3. Advise the parent about and offer referral to local early intervention or education programs; and
4. Give resource information to the parent of any child who is found to have a hearing loss, including but not limited to the degrees and effects of hearing loss, communication options, amplification options, the importance of medical follow up, and agencies and organizations that provide services to children with hearing loss and their families.



Virginia Early Hearing Detection and Intervention Program Advisory Committee Survey Cover Letter

Dear Virginia Early Hearing Detection and Intervention Program Advisory Committee Member:

The purpose of this short survey is to assess your perceptions of and experiences with the Virginia Early Hearing Detection and Intervention Program (VEHDIP). The survey will address issues related to data usefulness, data quality, timeliness, acceptability, flexibility, and stability of VEHDIP.

This survey is part of a formal evaluation effort currently underway in the Virginia Early Hearing Detection and Intervention Program.

If you have any questions about this survey or the evaluation, please contact Andrea Alvarez (andrea.alvarez@vdh.virginia.gov or 804-864-7648).

Best wishes,

Andrea Alvarez, MPH
CSTE Applied Epidemiology Fellow
Virginia Department of Health, Office of Family Health Services
Madison Building, 7th Floor
109 Governor St.
Richmond, VA 23219

Virginia Early Hearing Detection and Intervention Program Advisory Committee Survey

1. Agency/Organization Affiliation: _____
2. Position: _____
3. Length of time on Advisory Committee: _____

4. Please indicate the degree to which you agree or disagree with these statements:

	5	4	3	2	1
	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
The Virginia Early Hearing Detection and Intervention Program (VEHDIP) collects high-quality data.	5	4	3	2	1
VEHDIP is able to collect data on a regular basis.	5	4	3	2	1
VEHDIP collects data in a timely manner.	5	4	3	2	1
VEHDIP is able to manage data on a regular basis.	5	4	3	2	1
VEHDIP is able to provide data on a regular basis.	5	4	3	2	1
VEHDIP is able to assure that infants receive an initial hearing screening in the hospital prior to discharge.	5	4	3	2	1
VEHDIP is able to connect infants to audiologists in order to provide diagnostic evaluations.	5	4	3	2	1
VEHDIP is able to connect infants with diagnosed hearing loss to early intervention services.	5	4	3	2	1
VEHDIP is able to connect infants to a medical home.	5	4	3	2	1
VEHDIP is able to adapt to changing information needs.	5	4	3	2	1

5. In what context(s) have you used VEHDIP data? (check all that apply):

- Inform policy
- Make oral presentations
- Conduct scientific research (e.g. article, conference abstract)
- Produce written materials (e.g. reports, newsletters)
- I have not used VEHDIP data for public health action
- Other (specify): _____

6. Additional comments regarding VEHDIP or its surveillance data (optional):



COMMONWEALTH of VIRGINIA

Department of Health
P O BOX 2448
RICHMOND, VA 23218

Karen Remley, MD, MBA, FAAP
State Health Commissioner

TTY 7-1-1 OR
1-800-828-1120

Dear Audiologist,

The Virginia Early Hearing Detection and Intervention (VEHDI) Program is conducting a survey to evaluate the knowledge and opinions of audiologists regarding the VEHDI Program and EHDI services in Virginia.

The purpose of this survey is to assess audiological facilities' capacity to provide services to children age birth to 3 years, specifically the tools (i.e. equipment) used for diagnostic evaluations. We would also like to assess the current training needs for audiologists in regard to using equipment and referring children for early intervention services, so that we might tailor future training sessions to these needs. Responses to this survey will provide critical information as we work towards establishing a comprehensive system for reducing loss or delay to hearing evaluation follow-up.

Your response is important to us. All responses will be kept private and will only be reported in summaries with no names or other information that would identify your facility. For the facilities that have more than one location, we ask that one licensed audiologist who primarily works at each location be designated to complete this survey. If your facility only has one audiologist that splits his/her time between all of your locations, please have that audiologist complete a survey for each location.

Please complete and return the enclosed survey using the postage-paid envelope or complete online by going to: <http://vahealth.audiologistsurvey.sgizmo.com> by May 9, 2008.

Please feel free to contact me with questions or feedback regarding this survey, at 1-804-864-7716, or email michelle.ballard@vdh.virginia.gov.

Thank you in advance for your participation in this survey. Your individual input is needed and greatly appreciated.

Sincerely,

Michelle B. Ballard, MPH
Surveillance and Evaluation Coordinator
Virginia Early Hearing Detection and Intervention Program



Virginia Survey on Audiology Services: Diagnostic Audiology Services for Children Birth to 36 Months

SECTION I: General Information

1. Facility Name: _____

Name and Title: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: (____) _____ Fax: (____) _____

Email Address: _____

SECTION II: Knowledge of the Virginia Early Hearing Detection and Intervention (VEHDI) Program

2. How familiar are you with the VEHDIP Program? Please circle your responses.

- | | | | |
|-----|---|-----|----|
| 2a. | I know the 1-3-6 Goals | Yes | No |
| 2b. | I have read the VEHDIP Protocols for Audiologists | Yes | No |
| 2c. | <u>"Virginia's Resource Guide for Parents"</u>
is available at my practice | Yes | No |

3. The VEHDIP Program maintains a list of Approved Diagnostic Audiological Facilities. These facilities report that they have equipment to do clinical audiological evaluations for infants and young children. This list of approved sites is placed on the VEHDIP web site, is distributed to all Virginia birthing hospitals, and is printed on the back of every letter the VEHDIP Program sends to parents and primary care physicians.

3a. My facility is on this list:

Yes

No

Not sure

3b. If No, why not?

I am not aware of this list

I do not have the recommended equipment

Other, please explain: _____

3c. Would you like to receive more information about the criteria for being placed on this list?

Yes

No

SECTION III. Diagnostic Audiology Services for Children Birth to 36 Months of Age.

4. Please indicate the equipment you use in the assessment of hearing in children birth to 3 years of age by completing the following table. Check all that apply.

Equipment	I have this equipment in my facility.	I use this equipment in my facility.	I would like to receive additional training on using this equipment.	I am willing to provide colleagues training on using this equipment.
Auditory Brainstem Response Air Conduction (AC)				
Auditory Brainstem Response Bone Conduction (BC)				
Auditory Steady-State Response (ASSR) Audiometry				
Behavioral Observation Audiometry				
Conditioned Play Audiometry				
Conditioned-Orienting Response Audiometry				
Distortion Product Otoacoustic Emission (OAE)				
Reflexes				
Standard Audiometry				
Transient Evoked Otoacoustic Emission (OAE)				
Tympanometry				
Visual Reinforcement Audiometry				
Other, please specify:				

5. Please indicate the degree to which you agree with the following statement:

My facility has adequately trained personnel to diagnose hearing loss in children between birth and 3 years of age.

Strongly
Agree

Agree

Neutral

Disagree

Strongly
Disagree

6. In the last three months, approximately how many children between birth and 3 years of age have been diagnosed with a hearing loss by your facility?

- None
- 1-2
- 3-6

- 7-10
- More than 10
- Not sure

SECTION IV: Protocol for Reporting Confirmation of Hearing Loss

7. Identify your facility’s reporting protocol following confirmation of hearing loss. Check all that apply.

- Report to local department of education
- Report to local health department
- Report to local Infant and Toddler Connection (Part C) agency
- Report to parent
- Report to primary care physician
- Report to state department of education
- Report to VEHDI Program
- Other, please specify: _____

8. If you report to the VEHDI Program, indicate how you feel about the following statements: (If you do not report to the VEHDI Program, please go to question #9.)

	5 Strongly Agree	4 Agree	3 Neutral	2 Disagree	1 Strongly Disagree
It is easy to report hearing loss to the VEHDI Program	5	4	3	2	1
Reporting test results to the VEHDI Program poses a burden on my time	5	4	3	2	1
I am able to report results of audiologic evaluations in a timely fashion (within 2 weeks of screening)	5	4	3	2	1
The data that I provide to the VEHDI Program are of high quality	5	4	3	2	1
The VEHDI Program is able to keep the data I provide private and confidential	5	4	3	2	1
I see the value in reporting to the VEHDI Program	5	4	3	2	1
The VEHDI Program provides my facility with helpful information to give to parents of children with hearing loss	5	4	3	2	1

9. If you don’t report to the VEHDI Program, please explain why: _____

10. The Virginia Infant Screening and Infant Tracking System (VISITS) is a web-based reporting system currently used by hospitals to report results of hearing screenings.

10a. Have you heard of VISITS?

Yes No

10b. How helpful would it be to have access to VISITS and report evaluation results electronically?

Very helpful Somewhat helpful Not at all helpful

10c. If given the option, would you prefer to report evaluation results via VISITS or the current reporting format?

VISITS Current reporting format

SECTION V: Major Challenges and Barriers to Follow-up

The VEHDI Program would like your help in evaluating factors contributing to loss or delay to follow-up. Please check the response that best represents your opinion and/or experiences.

11. How often does each of the following pose a challenge/barrier to follow-up?

	5 Always	4 Nearly always	3 Sometimes	2 Seldom	1 Never
Family must travel an inconvenient distance	5	4	3	2	1
Pre-authorization requirements delay access to further evaluation	5	4	3	2	1
Lack of transportation to audiologist	5	4	3	2	1
Lack of health insurance impedes access to a primary care provider (PCP) and an audiologist	5	4	3	2	1
Language spoken by families prevents linkage to services	5	4	3	2	1
Privacy laws impede sharing between providers/across agencies	5	4	3	2	1
The VEHDI Program's reporting system (VISITS) is not accessible to audiologists	5	4	3	2	1

SECTION VI: Early Intervention Services

12. Please indicate the degree to which you agree with the following statements:

5	4	3	2	1
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

12a. Children with hearing loss develop normally in their language and social skills when they are enrolled in Early Intervention services before 6 months of age.

5	4	3	2	1
---	---	---	---	---

12b. I need more information about how to refer patients to local Early Intervention services.

5	4	3	2	1
---	---	---	---	---

13. Where does your facility refer children who have been diagnosed with hearing loss so that they receive early intervention services? Check all that apply.

- | | |
|---|--|
| <input type="checkbox"/> Care Connection for Children
<input type="checkbox"/> Department of Education
<input type="checkbox"/> Guide By Your Side
<input type="checkbox"/> Hearing Aid Loan Bank
<input type="checkbox"/> Infant & Toddler Connection of Virginia
(local Part C system)
<input type="checkbox"/> Local school district | <input type="checkbox"/> Private Intervention provider or agency
<input type="checkbox"/> School for the Deaf
<input type="checkbox"/> VEHDI Program
<input type="checkbox"/> Other family-to-family support program
<input type="checkbox"/> Other, please specify: _____

_____ |
|---|--|

14. What is the most common barrier preventing your patients from receiving Early Intervention (EI) services? Please check one response.

- Child is found ineligible for EI services
- Child is found eligible, but family is told he/she does not need services
- Family declines EI services (please provide information about why, if known: _____)
- Family is not aware of EI services
- Transient nature of families makes linkage to EI services challenging
- Other, please explain: _____

Current Report Capabilities in VISITS

- 1) Average time between hospital discharge date and entry into VISITS
- 2) Number of confirmed diagnoses by age (months)
- 3) Number of infants with hearing loss referred to Part C EI
- 4) Post-discharge initial screenings
- 5) Most recent diagnostic result for pass with followup
- 6) Age of referred infants at first diagnostic testing
- 7) Screening diagnosis comparison
- 8) Hearing loss/risk indicator comparison
- 9) Infant disposition report
- 10) Infants with a referred result at most recent followup
- 11) Infants with hearing loss but no followup
- 12) Infants not screened with risk indicators
- 13) Infants with guardians unable to be contacted by phone
- 14) Number of hearing cases with follow-up results
- 15) Average time between date received and screening date by audiological facility
- 16) Average time between date received and date created by audiological facility
- 17) Most recent follow-up screening result
- 18) Most recent diagnostic result for refers
- 19) Age of pass with followup infants at first diagnostic testing
- 20) Average time between date of birth and diagnosis
- 21) Infants diagnosed with hearing loss
- 22) Infants referred at most recent screening
- 23) Infants transferred out-of-state
- 24) Infants referred or pass with followup with no followup
- 25) Infants with risk indicators
- 26) Infants with letter returned

Risk Factors Associated with Permanent Congenital, Delayed-Onset, or Progressive Hearing Loss in Children, Joint Committee on Infant Hearing Guidelines, 2000 and 2007

Risk Indicator	2000	2007
Parent/caregiver concerns* regarding hearing, speech, language, or developmental delay	X	X
Family history* of permanent childhood hearing loss	X	X
Postnatal infections associated with sensorineural hearing loss* including bacterial and viral meningitis, herpes, and varicella	X	X
In utero infections such as cytomegalovirus*, herpes, rubella, syphilis, and toxoplasmosis	X	X
Head trauma*	X	X
Syndromes associated with progressive hearing loss* such as neurofibromatosis, osteopetrosis, and Usher syndrome.	X	X
Neurodegenerative disorders* such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich's ataxia and Charcot-Marie-Tooth syndrome	X	X
Neonatal indicators including hyperbilirubinemia (jaundice) that requires exchange transfusions, pulmonary hypertension associated with mechanical ventilation, and extra corporeal membrane oxygenation (ECMO)*	X	X
Physical findings such as stigmata that are associated with a syndrome known to include a sensorineural or conductive hearing loss or Eustachian tube dysfunction	X	X
Recurrent or persistent otitis media with effusion for at least three months	X	
Neonatal intensive care of more than 5 days or any of the following: exposure to ototoxic medications (gentimycin and tobramycin) or loop diuretics		X
Craniofacial abnormalities, including those that involve the pinna, ear canal, ear tags, ear pits, and temporal bone abnormalities		X
Chemotherapy*		X

* Indicators that are of greater concern for delayed-onset hearing loss

An Evaluation of Loss to Follow-Up in State EHDI Programs: Findings from the Virginia EHDI Program—Final Report Executive Summary

Each year, nearly 12,000 infants are diagnosed with hearing loss (Health Resources and Services Administration, 2002). Failure to diagnosis and begin intervention in a timely fashion can lead to delays and/or permanent impairment to an infant’s speech and language development (Karchmer & Allen, 1999). Recognizing the importance of early hearing detection and intervention, the Joint Committee on Infant Hearing (JCIH, 2000) issued a recommendation for universal infant hearing screening and benchmarks for follow-up known as the “1-3-6” Plan—screening by 1 month, diagnosis by 3 months, and initiation of intervention by 6 months of age.

In 1999, Virginia instituted the Code of Virginia (§32.1-64.1) and regulation 12 VAC 5-80, mandating hearing screening of all infants born at all hospitals with infant nurseries and all hospitals with neonatal intensive care services. The success of infant hearing screening has been unequivocal. An estimated 92% of all infants in the United States (Directors of Speech and Hearing Programs in State Health and Welfare Agencies, 2004) and 97% in Virginia are screened for early hearing loss. The full promise of early detection, however, cannot be fully realized unless commensurately high rates are achieved for follow-up to rescreening, diagnosis, and early intervention. The Centers for Disease Control and Prevention (CDC) estimates that nearly half of infants who are referred for diagnosis do not receive it by 3 months of age; a third of those infants diagnosed with hearing loss do not initiate intervention by 6 months of age (CDC, 2003).

In an effort to more fully understand the factors that underlie the failure to follow up to evaluation, diagnosis, and intervention in a timely fashion, the CDC Early Hearing Detection and Intervention Program (EHDI) awarded to RTI International a contract to comprehensively evaluate the loss to follow-up in five states: Arkansas, Massachusetts, Michigan, Utah, and Virginia. The evaluation project was planned and conducted collaboratively with CDC technical officers and the state EHDI coordinators. The specific evaluation objectives of the project were:

- To investigate and document factors that contribute to loss to follow-up including:

- structural barriers: state policies and regulations, organizational systems, availability of screening and follow-up services, availability of equipment, and transportation;
- financial barriers: health insurance coverage of screening services and follow-up evaluations; and
- personal barriers: norms, beliefs, attitudes, knowledge, social support systems, maternal age, parity, and ethnicity.

To provide information that will inform strategies and policies to increase the rates of follow-up:

- create a program that is more responsive to consumers' needs, and
- improve the cultural competency of the program.

The evaluation project involved three data collection activities: (1) focus groups with state EHDI stakeholders (parents, providers, hospital staff, advocates, and state EHDI staff); (2) a Maternal Exit Survey of post-partum women prior to hospital discharge; and (3) a Computer-Assisted Telephone Interview (CATI) survey of women whose infants had been referred for additional rescreening or diagnosis. The use of these three information sources allowed the study to gain a fuller understanding of the challenges of ensuring early hearing screening and intervention in Virginia and the United States. The purpose of this report is to present the findings of the project's data collection activities in Virginia. In this chapter we summarize the key highlights of those findings.

Virginia Focus Groups

Focus groups with key EHDI stakeholder groups in Virginia revealed the following major challenges and barriers to follow-up:

- A shortage of audiologists primarily due to lack of or inadequate insurance reimbursement for diagnostic services.
- A lack of standards for counseling and referring families resulting in uneven quality of these screening procedures.

- No systematic way to inform providers (audiologists and physicians) of the screening results; the onus lies largely with the parent to bring documentation to the visit but they often do not.
- The lack of medical home and/or having a pediatrician identified prior to birth leaves families with fewer tangible links to the follow-up process.
- The designated “medical home” does not in fact coordinate the various specialized care needs of the infant but instead typically operates in isolation from the other providers involved in the follow-up and intervention process.
- Lack of or inadequate private and public health insurance coverage to cover all the costs of follow-up and intervention. In some cases these costs are covered but parents are misinformed about their coverage or are not informed about public programs such as Part C that will cover them.
- The cumbersome, lengthy process of obtaining referrals and approvals from private and public insurers for intervention that can delay the process by weeks and months.
- Inadequate information exchange among professional staff working with families; staff are not always aware of all the programs available to support families.
- Some physicians downplay the importance of the screening results and/or still promote a “wait and see” approach which sends a mixed message to parents who are receiving other information and counseling, encouraging them to take the referrals seriously and address them in a timely fashion.
- A lack of knowledge about hearing loss among extended family and friends can create conflict and stress for families in the midst of the diagnostic or intervention process.
- A lack of or perhaps insufficient linkages to family support services; parents noted a need for more family-to-family networks.

□ Cultural barriers related to language and stigma against disability make it difficult for families to understand the hearing loss issue, accept it, and then address it.

Maternal Exit Survey

The Maternal Exit Survey, conducted in four hospitals in Virginia, revealed the following key findings regarding screening practices and maternal knowledge, attitudes, and beliefs about hearing loss and screening results:

□ Two thirds of respondents (65%) reported that had received information regarding hearing screening *prior* to hospital admission.

□ Nearly three quarters of the respondents (73%) reported that they had received information about hearing screening since being admitted to the hospital.

□ Two thirds of the respondents (66%) indicated that a hospital staff person had talked to them about the hearing screening *prior* to the procedure.

□ Less than half of respondents (39%) reported receiving the results of their infant's hearing screening, both in person and in writing.

□ A third of the respondents who completed the Spanish version of the survey (33%) reported that they had not received written materials regarding hearing screening in Spanish.

□ Over half of respondents who completed the Spanish version of the survey (55%) indicated that no one had explained the results of the hearing screening in Spanish.

□ A majority of the respondents (76%) indicated they received all the information they needed regarding the hearing screening, and that the hospital staff had spent enough time explaining the results (75%).

□ The majority of the respondents (88%) indicated that they understood the meaning of the hearing screening test result.

- Of those respondents whose infant *did not pass* the hearing screening test:
 - Three quarters believed the hearing screening result to be true (75%).
 - Nearly all indicated they knew what to do next (94%) and thought it was important to retest soon (100%).
 - Nearly three quarters (73%) indicated feeling anxious about the result.
 - Over half (56%) indicated that the hospital had made a follow-up appointment.
 - A quarter (24%) had not received any information about where to go for followup evaluation.

CATI Survey

The Computer Assisted Telephone Interview (CATI) Survey conducted with 190 women whose infants had not passed the initial hearing screening revealed findings regarding screening and follow-up practices, the information provided, maternal knowledge, attitudes and beliefs about hearing loss, the hearing screening, and follow-up re-screening and diagnostic evaluation.

Information about Hearing Screening

- A minority of respondents (12%) remembered receiving information regarding the hearing screening test *prior* to hospital admission.
- Nearly a third of the respondents reported that they did not fully comprehend the materials provided on hearing screening; some understood only some portion of the materials (18%), a few reported that they did not understand the materials all that well (4%), or had not read the materials (6%).
- Among Spanish-speaking mothers, the majority (81%) received hearing screening materials in Spanish but less than half (37%) did not have anyone explain to them the hearing screening results in Spanish.

The Hospital Hearing Screening Experience

- Almost all respondents had received a hearing screening test (95%) and the results (97%) prior to hospital discharge.

- Two thirds of the respondents (65%) remembered receiving both verbal and written confirmation of the results of their infant’s hearing tests.
- Almost all respondents indicated that they received all the information they needed regarding the hearing screening test (89%) and a somewhat smaller majority thought that the hospital staff had spent enough time explaining the results (82%).

Beliefs and Attitudes about the Hearing Screening Test Result

- A majority of the respondents indicated that they understood the meaning of the hearing screening test result (89%) and believed it to be true (84%).
- Although nearly all respondents indicated they understood the results, half thought the hearing screening test result meant the infant had “*fluid in his or her ears and it was nothing to worry about*” (47%) or that the infant “*was probably okay but there was a problem with the test*” (48%). A third (29%) did not realize the result meant the child should be retested soon and a quarter (26%) thought the infant had hearing loss.

Follow-Up Procedures

- Almost all the respondents (93%) indicated that they understood what to do next in terms of follow-up and completed their follow-up appointment (96%).
- Just under two-thirds of respondents (61%) had the hospital or doctor’s office make the follow-up appointment; another third (31%) received a list of audiologists.
- More than half of respondents indicated that no one had called (55%) or sent them a letter (54%) to remind them about their follow-up appointment.
- Eighty-six percent of respondents made an appointment for a follow-up evaluation by 1 month post-discharge from the hospital.
- Ninety-one percent of the respondents whose infant had not passed the follow-up evaluation had undergone further diagnostic evaluation.

Family Social Support Services

□ Of those respondents whose infants had been definitely diagnosed with hearing loss, the majority (83%) had not received any information about family-to-family support networks.

Maternal Anxiety

□ Overall, a majority of the respondents (86%) expressed anxiety about the results of the hearing screening result.

□ Among those whose infants had been referred to diagnostic evaluation, under half (45%) reported that they were “very anxious” about the effects of a possible hearing loss in their infant.

Conclusions and Recommendations

Based on the findings of this evaluation, we offer some key conclusions and recommendations with implications for EHDI programs and policies.

□ A shortage of audiologists could pose an impediment to the timely follow-up of infants referred for additional follow-up. One factor cited for the shortage is inadequate insurance reimbursement. Efforts to examine this issue more closely and identify the appropriate programmatic and policy solutions are warranted.

□ Physician knowledge and attitudes about early hearing screening could potentially influence parents in both negative and positive ways with respect to follow-up compliance. Continuing education and promotion of the benefits of early screening, detection, and intervention are needed to reinforce the training of younger physicians and to dispel the outdated notions of an older generation of physicians.

□ Extended family and friends’ lack of knowledge and understanding of hearing loss, its detection and intervention, can be a source of conflict and misinformation. Education and counseling activities should extend beyond the immediate family to significant others so that they can offer support that is informed, positive, and empowering.

- The majority of women do not remember receiving information about hearing screening and hearing loss during the prenatal period. Hospital stays are typically too short and rushed to provide an effective environment for education and counseling. More effort should be directed to ensuring that *all* pregnant women receive education and counseling on hearing screening.
- Educational materials are not universally understood or even read. Attention should be given to their comprehension and appeal. This study was not able to distinguish between lack of use of informational materials or a lack of recall on the part of respondents. It is possible that the low rates of recall of information about hearing screening summarized above may reflect a sense that materials are not compelling or presented in a way that makes them memorable. The fact that some respondents reported that they did not fully understand materials suggests that it will be useful to more rigorously assess the materials that are presented and to assess the nature of their presentation.
- Although women appear to think in a global sense that they understand the test results and have all the information they need, their misconceptions about the hearing screening test reveal a potential lack of comprehension of the results. This lack of understanding could potentially be addressed through education and counseling in the prenatal period, both written and oral confirmation of the results, and more intensive counseling and education during the hospital stay.
- Spanish materials are not widely disseminated to all who need them and more could be done in this regard. Efforts should be directed at ensuring that all non-English speakers receive the results of the hearing screening in their native language.
- The medical home is an important factor in ensuring access to health care. Families that have no established link to a health care provider for their infant will likely find it more difficult to navigate the follow-up process in a timely manner. Identification of these families prior to discharge so that they can be tracked and supported more intensively may prevent or mitigate loss to follow-up.

- Systematic links to follow-up were not uniformly available to all women. Overall, completion rates to follow-up and diagnosis were quite high; however, additional supports such as scheduling appointments prior to discharge and reminder calls and letters could promote timeliness for those high-risk families who face various barriers to accessing health care.

- The majority of women whose infants did not pass the hearing screening test experience some level of anxiety. Post-test counseling should address parental concerns and worries, but should do so in a way that stresses the importance of follow-up.

- The majority of women who have an infant with a diagnosed hearing loss would like to have another family to connect with but the links to family support networks appear to be largely lacking and need to be improved.

VEHDIP: Virginia Early Hearing Detection and Intervention Program Surveillance Methodology Evaluation Plan

Use the *Updated Guidelines for Evaluating Public Health Surveillance Systems: Recommendations From the Guidelines Working Group* published by the CDC². Summarized below are the steps for evaluating a surveillance system, tailored specifically to VEHDIP's system.

1. Engage the Stakeholders in the Evaluation

A. Contacts may include:

- i. VEHDIP staff members
- ii. VEHDIP Advisory Committee members
- iii. Hospitals that perform newborn hearing screenings
- iv. Audiologists that perform newborn hearing screenings
- v. Early Intervention providers
- vi. Parents of children who are deaf or hard-of-hearing
- vii. EHDI staff of other states or national EHDI staff at CDC

B. Contact may be in the form of:

- i. E-mail / letter informing them of the evaluation
- ii. Survey (online or mail) instrument
- iii. Informal discussion on phone or in-person
- iv. Structured interviews

2. Describe VEHDIP

In this section, provide background to support why Virginia has a surveillance system for newborn hearing loss and describe how it operates. Use the most current data, cost estimates, surveillance system information, and research publications available.

A. Describe the public health importance of newborn hearing loss

- i. Compare Virginia with published national rates/estimates and use VEHDIP published statistics

- ii. Indices of frequency and severity: prevalence of all newborn hearing loss, spectrum of loss (mild→severe), type of loss (conductive vs. sensorineural, bilateral vs. unilateral)
- iv. Disparities associated with newborn hearing loss: racial/ethnic, social, disabilities
- v. Costs associated with newborn hearing loss
- vi. Preventability (primary, secondary, tertiary prevention)
- vii. Public interest

B. Describe the purpose and operation of VEHDIP

- i. Planned uses of the data from VEHDIP
- ii. Case definition of hearing loss
- iii. Legal authority for data collection
 - a. Mandated in 1999 by *Code of Virginia* (§32.1-64.1) and regulation 12 VAC 5-80
- iv. Describe the organizational location of VEHDIP
- v. Describe the relevant administrative, geographic, political, or social context in which the evaluation will be completed
- vi. Describe the level of integration with other systems
 - a. VISITS is integrated with Virginia Newborn Screening Services, VaCARES
 - b. Can data be linked to other databases (birth certificates, hospital discharge data, etc.)?
- vii. Draw a flow chart of the system
- viii. Describe the components of VEHDIP, including the following:
 - a. Population under surveillance (Virginia birth population—data available from DataMart)
 - b. Period of time of the data collection
 - c. What data are collected and how
 - d. Reporting sources—hospitals and audiologists
 - e. Data management policies, compliance with standards for formats and coding

- f. Data analysis plans and dissemination plans
- g. Privacy policies, confidentiality policies, and system security
- h. Records management policies

C. Describe the resources used to operate VEHDIP

- i. Funding sources
- ii. Personnel requirements
- iii. Other resources

3. Focus the Evaluation Design

- A. Determine the specific purpose of the evaluation
- B. Determine which stakeholders will receive the findings and recommendations of the evaluation
- C. Specify the questions that will be answered by the evaluation
 - i. Stakeholders can help to narrow the scope of the evaluation. Consider evaluating components or attributes that have not been recently evaluated or new components that have entered the system (e.g. VISITS II).
- D. Determine the standards for assessing the performance of the system
 - i. National Birth Defects Prevention Network Guidelines for Conducting Birth Defects Surveillance
 - ii. CDC's Updated Guidelines for Evaluating Public Health Surveillance
 - iii. Review evaluations of other states' EHDl systems
 - iv. Compare data to national goals (1-3-6)

4. Gather Credible Evidence Regarding the Performance of the Surveillance System

- A. Indicate the level of usefulness of VEHDIP.
 - i. Does VEHDIP address its stated goals/objectives?
 - ii. How does VEHDIP affect policy decisions and other public health programs?

- B. Describe each surveillance system attribute as it applies to VEHDIP.
- i. Simplicity: How complicated is the structure of the system and how easy is it to operate?
 - a. Is it easy for data providers to report to VEHDIP?
 - b. Is it easy to analyze data from VISITS?
 - c. If variables are collected by several data sources, are they in similar formats?
 - ii. Flexibility: Is the system able to adapt to changing information needs or operation conditions with little additional time, personnel, or funds?
 - a. How does system react to changes in funding?
 - b. How does system adapt to new JCIH recommendations?
 - iii. Data quality: How complete and valid are the data recorded by the system?
 - a. What percentage of data elements is missing or unknown?
 - b. How do data compare to JCIH benchmarks?
 - c. Are any data elements optional that should be mandatory?
 - iv. Acceptability: How willing are persons and organizations to participate in the system?
 - a. Percentage of parents who refuse screening
 - b. Conduct user satisfaction survey
 - c. Are hospitals and audiologists reporting in a timely manner?
 - v. Sensitivity: Proportion of cases of hearing loss detected by the surveillance system. Also includes ability to detect “outbreaks” of hearing loss and monitor changes in health patterns over time.
 - a. Calculate expected rate for Virginia and compare to what is detected by VEHDIP
 - b. Has the system become better able to identify cases of hearing loss over time?
 - c. Is the system able to detect clusters of hearing loss?

- vi. Predictive value positive: Proportion of reported cases of hearing loss (failed hospital screen) that are confirmed hearing losses (diagnosed hearing loss).
 - a. Make comparisons between failed hospital screens and diagnostic audiological evaluations.
- vii. Representativeness: Does the system accurately describe the occurrence of hearing loss over time and its distribution in the population by place and person?
 - a. Calculate expected rate of hearing loss and compare to what is detected by the surveillance system.
 - b. What percentage of Virginia births are covered by VEHDIP?
 - c. Identify regions with higher rates of loss to follow-up
 - d. Use GIS to evaluate representativeness.
- viii. Timeliness: How long does it take between steps in the surveillance system?
 - a. How long do hospitals or audiologists take to report results?
 - b. How long between failed initial screening and diagnosis?
 - c. How well is Virginia meeting 1-3-6 goals?
- ix. Stability: How reliable and available is VEHDIP? How well is the system able to collect, manage and provide data without failure? How often is the system operational when needed?
 - a. Is funding for the project secure?
 - b. How often do system outages or IT problems occur?

5. Justify and State Conclusions, and Make Recommendations

- A. State conclusions with justification from gathered evidence and analyses.
 - i. Does VEHDIP address a public health problem in Virginia?
 - ii. Is VEHDIP meeting its goals/objectives?
 - iii. Has VEHDIP been updated to meet any previous evaluation recommendations? Why or why not?

- B. Make recommendations based on conclusions, taking into account the impact of the recommendations.

6. Ensure Use of Evaluation Findings and Share Lessons Learned

- A. Share findings with stakeholders in appropriate forums
 - i. VEHDIP Advisory Committee meeting
 - ii. Other stakeholder meetings (statewide conferences)
- B. Share findings in appropriate formats
 - i. Full evaluation report to VEHDIP staff
 - ii. Fact sheet or executive report to parents, audiologists, hospitals, or similar audiences
 - iii. If desired, post to Web site to reach wider audience
- C. Other possible dissemination activities
 - i. Submit evaluation as an abstract to a national EHDI meeting or other conference (MCH-Epidemiology, American Public Health Association, etc.)
 - ii. Submit evaluation to a journal for publication
 - iii. Video conference with hospitals, audiologists, Early Intervention providers, or other stakeholder groups

APPENDIX B: Tables

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Variables Reported by Hospitals and Audiologists

Data Element	Hospitals	Audiologists
Child Last Name	Required	Yes
Child First Name	Required	Yes
Child Middle Name	Optional	Yes
Child Name Suffix	Optional	No
Child's Name at Birth (if different)	No	Yes
Child Sex	Required	Yes
Child's SSN	Optional	No
DOB	Required	Yes
Race	Required	No
Ethnicity	Optional	No
Birth Hospital	Required	Yes
Child Address	No	Yes*
Child City/State/Zip	No	Yes*
Child Phone	No	Yes*
Hospital Medical Record #	Optional	Yes
Birth Certificate #	Optional	No
Mom's Last Name	Required	Yes
Mom's First Name	Required	Yes
Mom's Middle Name	No	Yes
Mom's Maiden Name	Optional	Yes
Mom's SSN	Optional	No
Father's First Name	Required	No
Father's Last Name	Required	No
Primary Contact Name	Required	No
Primary Contact Relationship	Optional	No
Primary Contact Address	Optional	No
Primary Contact City	Optional	No
Primary Contact State	Optional	No
Other Contact Last Name	No	Yes
Other Contact First Name	No	Yes
Other Contact Middle Name	No	Yes
Other Contact Relationship	No	Yes
Child's PCP Name	Required	Yes
Child's PCP Practice Name	Optional	Yes
Child's PCP Address	Optional	No
Child's PCP City	Optional	No
Child's PCP State	Optional	No
Child's PCP Phone	No	Yes

*Unclear if information pertains to child, mother, other contact or primary contact

Sensitivity and Predictive Value Positive

Sensitivity: *proportion of cases of hearing loss detected by VEHDIP*

Year	Observed Cases	Expected Cases (Estimate)
2002	109	100-300
2003	103	100-300
2004	122	100-300
2005	129	100-300
2006	135	100-300
TOTAL	598	

Predictive Value Positive: *proportion of individuals who are referred for an audiological evaluation who actually have hearing loss*

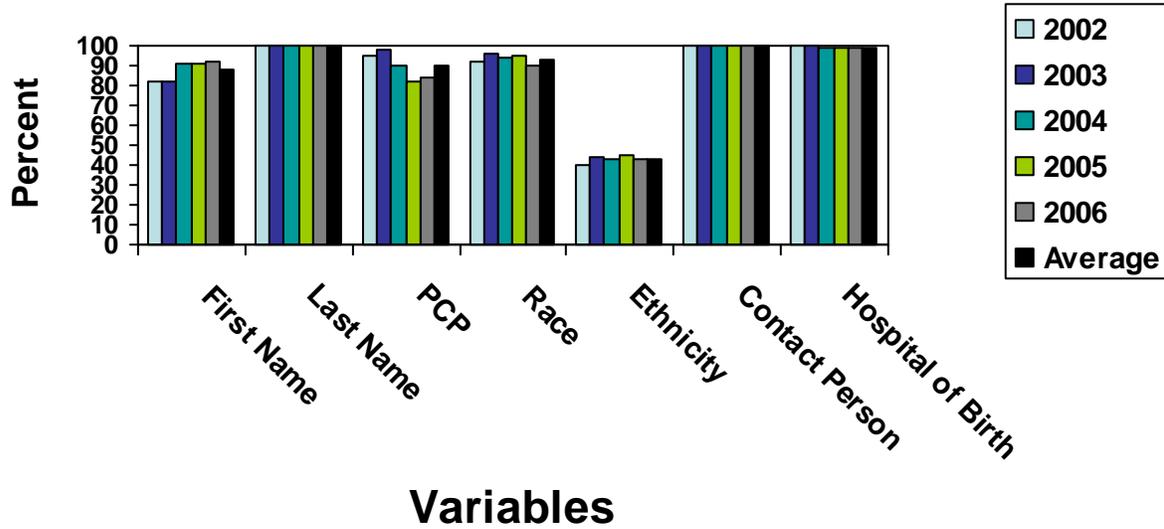
Ear	Received Diagnosis (A)	Referred on Initial Screening (B)	Received Follow-Up (C)	PVP of Diagnosis (of All Who Were Referred on Initial Screening) (A/B)	PVP of Diagnosis (of Those Who Received Follow-Up) (A/C)
One or Both Ears	437	14,216	11,366	3.1 %	3.8%
Left Ear	335	10,136	8,102	3.3%	4.1%
Right Ear	252	9,188	7,319	2.7%	3.4%

APPENDIX C: Figures

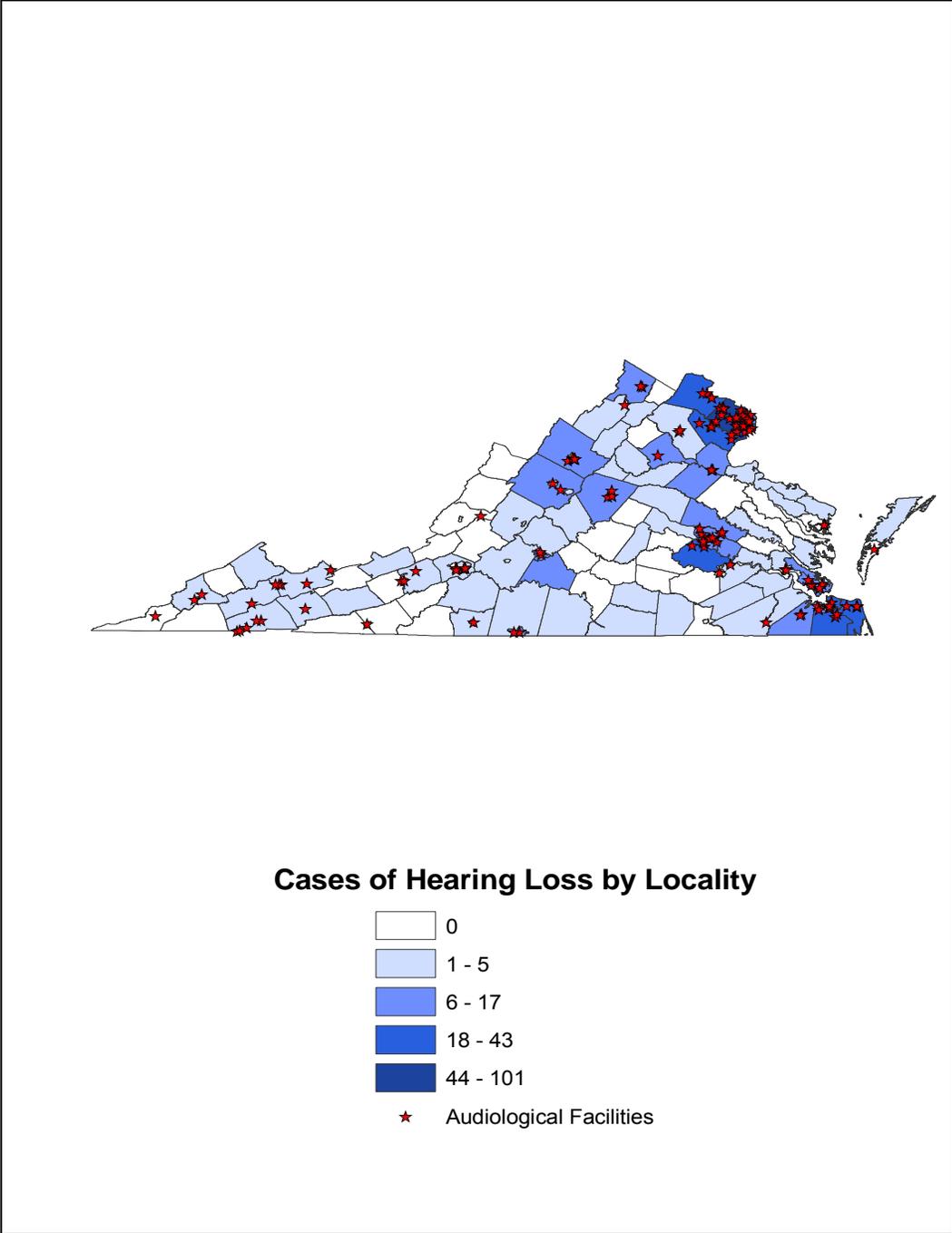
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Data Quality: Percentage of Valid Responses for Selected Variables

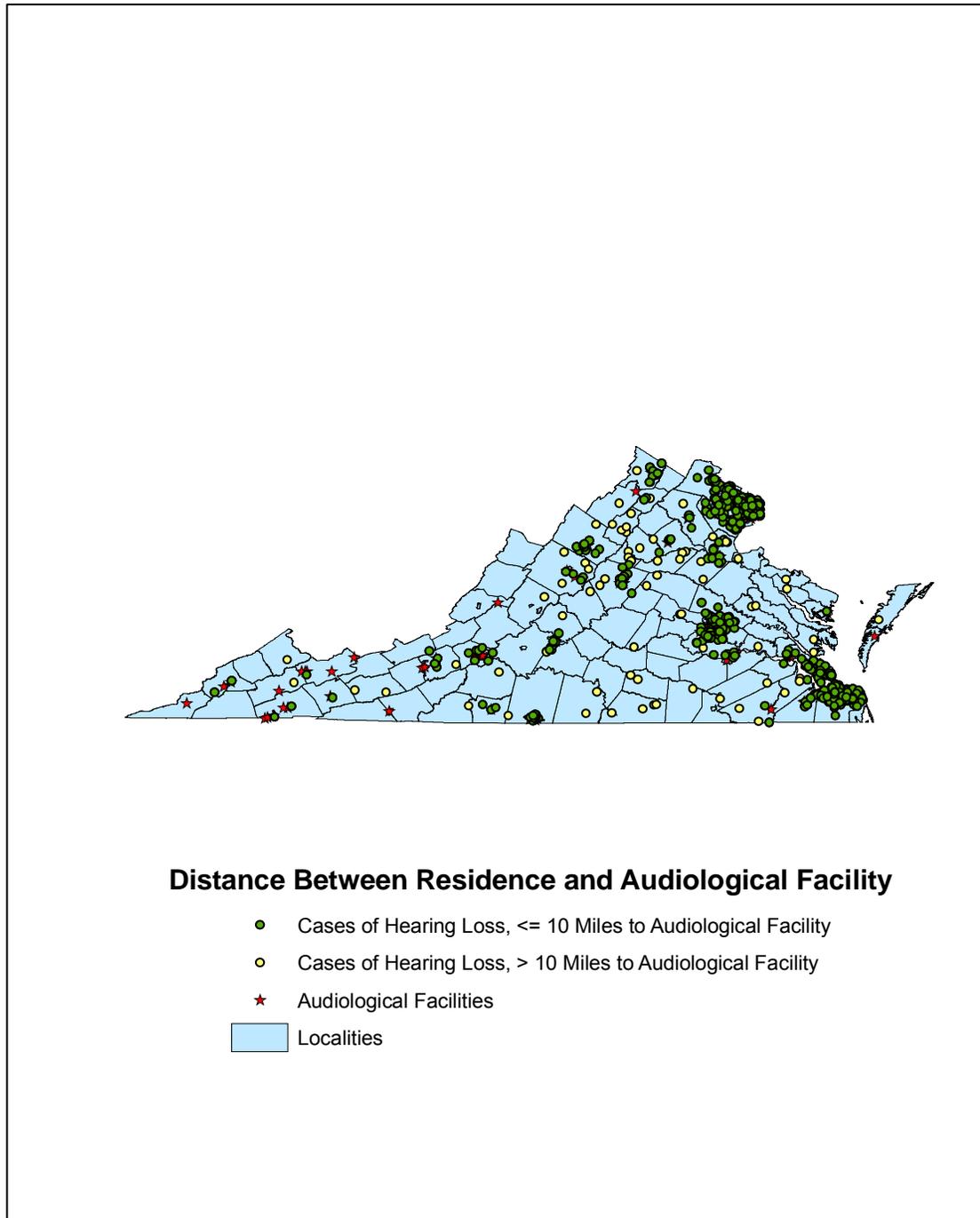
Percentage of Valid Responses for Selected Variables, 2002-2006



Representativeness: Map 1

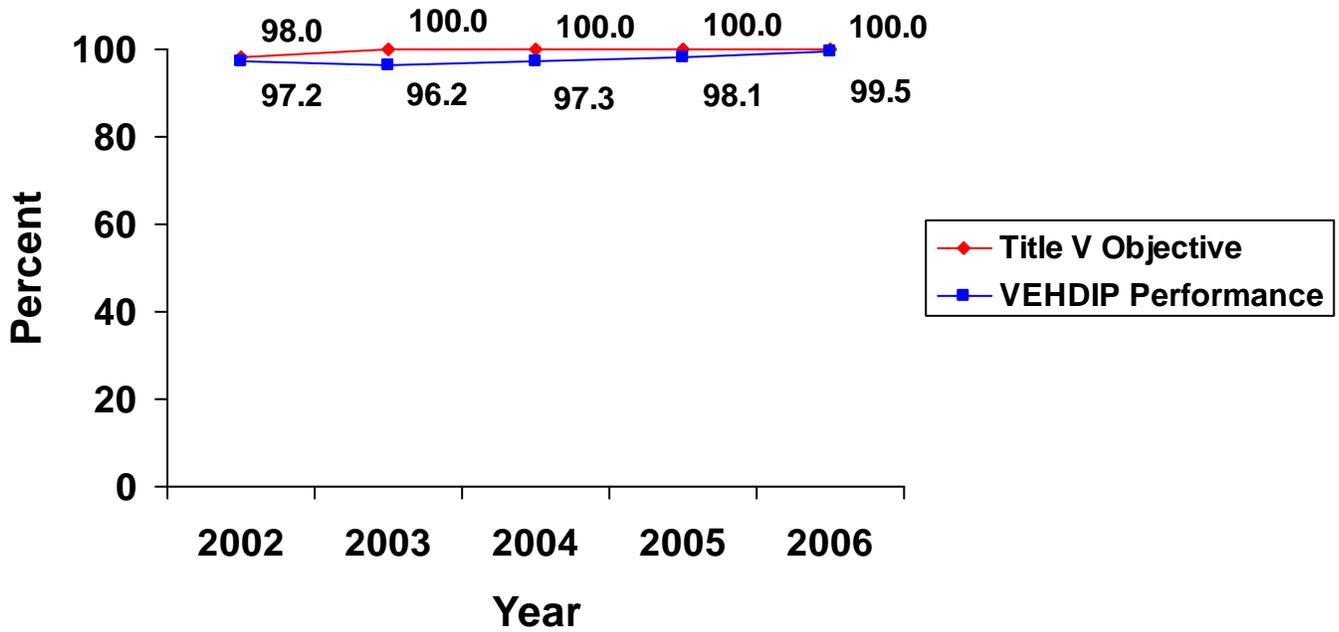


Representativeness: Map 2



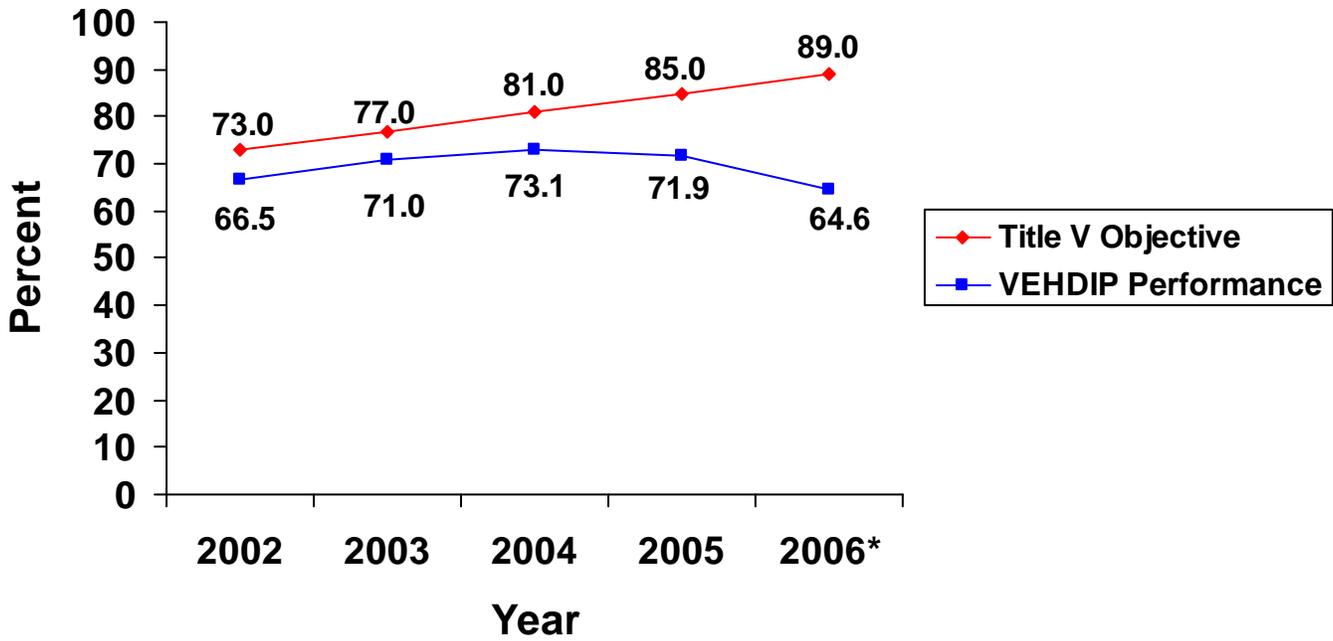
Timeliness: Title V National Performance Measure 12

Percent of Newborns Who Have Been Screened for Hearing Before Hospital Discharge by Year, 2002-2006



Timeliness: Title V State Performance Measure 3

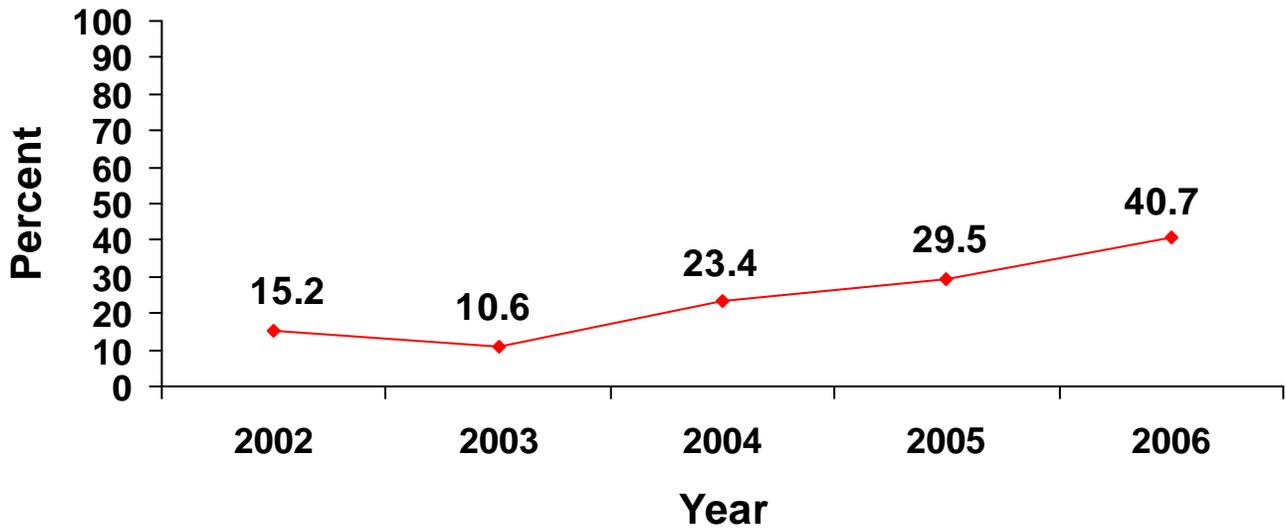
Percent of Newborns Screened For Hearing Loss Who Receive Recommended Follow-Up Services by Year, 2002-2006



*: Indicator changed to “The percent of newborns who fail the hearing screening and who receive a diagnosis before 3 months of age”

Timeliness: Hospital Reporting

Percent of Hospitals Who Submit Hearing Screening Results Within One Week of Discharge by Year, 2002-2006



Timeliness: Audiologist Reporting

Percent of Audiologists Who Submit Diagnostic Evaluation Results Within Two Weeks of Evaluation by Year, 2002-2006

