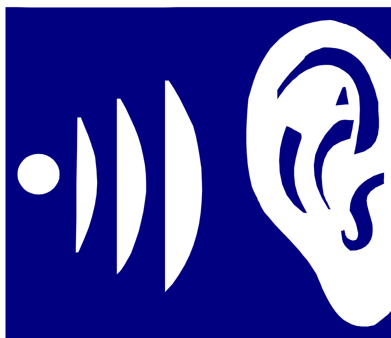
Virginia Early Hearing Detection And Intervention Program 2003 Annual Report

Background:

Hearing loss is the nation's number one birth disorder, affecting between 1 and 3 infants out of 1,000. Based on this incidence, as many as 300 children born in Virginia could be diagnosed with hearing loss each year. Without universal screening, the average age of a child diagnosed with hearing loss is between 2 and 3 years of age. With universal screening, hearing loss can be diagnosed within the first few weeks of life. When children are identified with hearing loss early and receive intervention services to help develop signed or spoken language, they have the best chance to learn. The American Academy of Pediatrics, the American Academy of Audiology, the Joint Committee on Infant Hearing, and the National Association of the Deaf have recommended that all babies be screened for hearing loss before they leave the hospital. Universal newborn hearing screening in the hospital prior to discharge has become standard practice in Virginia.

The *Code of Virginia*, sections 32.1-64.1 and 32.1-64.2, requires all hospitals to screen newborns prior to discharge. Hospitals also are required to identify children at risk for developing hearing loss in childhood and report these results to the Virginia Department of Health (VDH). In addition, audiologists are required to send reports to VDH on all children seen for audiological follow up. VDH collects, maintains, reviews, and evaluates these data. VDH also provides training and technical assistance to the hospitals and makes available follow-up information and services to parents.



Mission:

The mission of the VDH Virginia Early Hearing Detection and Intervention (VEHDI) Program is to minimize or eliminate communication disorders resulting from hearing loss. This mission is being accomplished in part by implementing the following Centers for Disease Control and Prevention (CDC) Early Hearing Detection and Intervention (EHDI) recommendations, often referred to as the "**1-3-6 Plan**".

- All infants will be screened for hearing loss prior to hospital discharge or by **1** month of age.
- All infants who do not pass their hearing screening will have a diagnostic evaluation that either confirms or rules out the presence of hearing loss by **3** months of age.
- All infants with a confirmed hearing loss will receive early intervention services by **6** months of age.

2003 Program Highlights:

- Virginia received a rating of "Excellent" from the World Council on Hearing Health Deafness Research Foundation, formerly known as the National Campaign for Hearing Health. In order to receive this rating, the state had to document a minimum-screening rate of 94.0 percent as well as have an established system of follow up.
- Over 700 professionals received the Providing Resources and Education for Professionals (PREP) training, which was completed in June 2003. VDH continued its collaboration with the Virginia Department of Education and the Partnership for People with Disabilities to present the training modules. The training assists educators, therapists, healthcare providers and others to acquire competencies needed in working with infants, toddlers, and primary-aged children who are deaf or hard of hearing and their families.
- In order to better identify children who need intervention from EHDI and other VDH programs, such as the Birth Defects Registry, VDH collaborated with the Part C Early Intervention System to establish an automatic referral process. This was accomplished through linkages between the VDH integrated database, Virginia Infant Screening and Infant Tracking System (VISITS), and the electronic Part C data management system, Infant and Toddler Online

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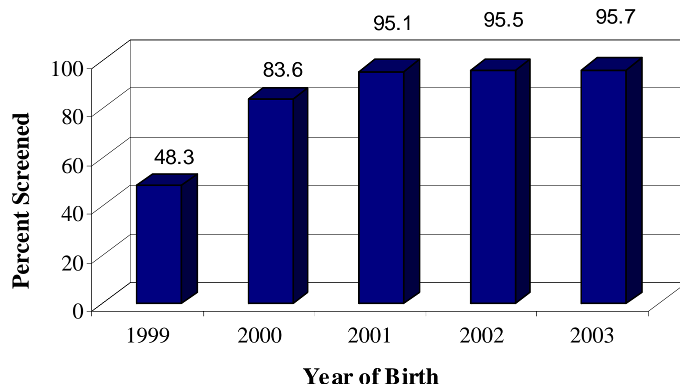
Figure 1: Percent Screened Before 1 Month of Age, 1999-2003



As Figure 1 shows, the screening rate of infants screened for hearing loss before 1 month of age in Virginia has dramatically increased over the last five years, from 48.3 percent in 1999, to 95.7 percent in 2003. Most hospitals in Virginia screen more than 99 percent of the newborns born in their facility. Very few infants are missed in the hospital (less than 0.5 percent), and almost no parents refuse the screening (less than 0.03 percent). The disparity between the hospital screening rate (99.7 percent) and the overall statewide screening rate (95.7 percent) is explained by births at military hospitals, birthing centers, and home births, which are not required by law to be reported to VDH. Births at military hospitals, birthing centers and home births accounted for 6 percent of the 2003 births. While all military hospitals report that they are screening infants for hearing loss, VDH does not receive all of the data.

The National Center for Hearing Assessment and Management (NCHAM) at Utah State University surveyed EHDI coordinators from all 50 U.S. states and the District of Columbia . The survey was developed to obtain data that would represent the status of EHDI programs in general and uncover areas where changes, enhancements, or improvements would make EHDI programs more effective. The survey categories included screening, diagnosis, early intervention, medical home, family support, evaluation, tracking, advisory group, financing, and obstacles. Virginia ranked third nationwide in the percentage of infants screened. Table 1 highlights the survey results.

One of the goals of a newborn hearing screening program is to decrease the average age at which children with congenital hearing loss are identified. Table 2 illustrates the number of infants reported to VDH who

Table 1: State EHDI Survey

Survey Questions	National Average	Virginia
Percent of babies born during the 4th quarter 2003 screened for hearing loss prior to hospital discharge	89.7%	99.7%
Percent of birthing facilities doing universal newborn hearing screening at the end of December 2003	86.6%	100%
Percent of babies born in 2003 and referred from screening (47 states responded)	5.6%	2%
Percent of babies born in 2003 and referred, for whom hearing status was confirmed by 3 months of age (36 states responded)	55.1%	70%
Percent of infants born in 2003, identified with permanent hearing loss, who began appropriate early intervention by 6 months of age	48.7%	70%
Number of states having a hearing aid loaner bank for infants and toddlers who need hearing amplication (1 state did not respond)	20	0

were born in a given year and have now been identified with a hearing loss, as well as the average and median age at diagnosis. Median age is defined as the age at which half of all cases were diagnosed earlier and half later and is generally a more accurate indicator of the "typical" age. The median and average age at diagnosis are expected to increase because children diagnosed with hearing loss after the publication of this report will be older than those already identified. The number of infants reported to VDH falls short of the 300 expected cases annually. VDH is tracking more aggressively all infants who have not passed their follow-up hearing screening.

Table 2: Number and Age at Diagnosis with Hearing Loss

Infants born in year	# Diagnosed with Hearing Loss	Median Age at Diagnosis (in months)	Average Age at Diagnosis (in months)
1999	32	9.0	15.5
2000	72	5.4	13.0
2001	71	6.9	11.6
2002	70	4.2	5.9
2003	65	3.4	4.8

Figure 2: Number of 2003 Hearing Loss Cases Reported by Health Planning Region

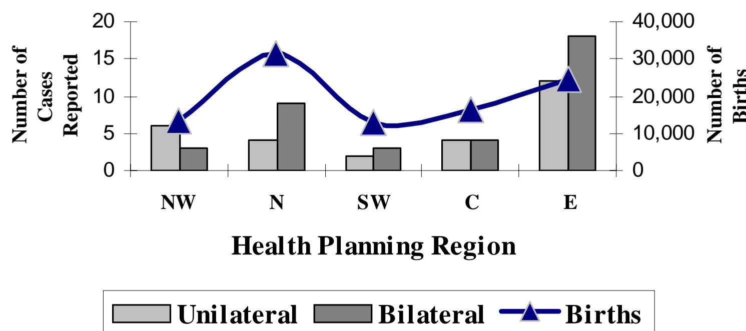


Figure 2 and Table 3 present data as reported regionally. There are more diagnosed cases of bilateral hearing loss reported to VDH than unilateral hearing loss, as seen in Figure 2. This is inconsistent with national trends, and it is believed that unilateral hearing loss may be a large contributor to the shortfall of identified hearing loss cases reported to VDH. Eastern Virginia (Planning Region 5) reported the greatest number of cases and Southwest Virginia (Planning Region 3) the fewest. As seen in Table 3, follow-up rates between Health Planning Regions vary.

Table 3: Follow Up Rates by Health Planning Region for Infants Born in 2003

Health Planning Region	Number referred for follow up	Number receiving follow up	Percentage receiving follow up
1—Northwest Virginia	534	466	87.3%
2—Northern Virginia	1,150	954	83.0%
3—Southwestern Virginia	221	157	71.0%
4—Central Virginia	392	291	74.2%
5—Eastern Virginia	798	553	74.9%

(2003 Program Highlights continued)

Tracking System (ITOTS). VDH also piloted an At Risk Module within VISITS, which allows hospital discharge planners to record information on infants who are eligible for Part C services. Once implemented statewide, these processes will enable both the hospitals and VDH programs to communicate referrals directly to local councils, to obtain confirmation of a child's enrollment in early intervention services, and eventually, to document and monitor intervention outcomes.

- The VEHDI Program expanded its Web site (www.vehdis.info) to include complete curricula and materials for the targeted groups—hospital staff, primary medical care providers, and audiologists—as well as PREP Awareness Level training. The site assures that information is readily available for training and education efforts in the future.
- Following a staffing delay, the positions of the Follow-Up Coordinator and Program Support Technician were filled. Being fully staffed markedly increased tracking and follow up of newborn hearing screening. An added benefit for families is that the new Follow-Up Coordinator is fluent in both English and Spanish.
- VEHDI program staff worked in partnership with the Virginia Center for Heath Outreach to create opportunities to educate community health workers about EHDI and state resources. Community health workers can incorporate information about the importance of screening and follow up as they conduct home visits for pre– and post-natal care.
- VDH surveyed hospital EHDI program staff to assist with planning for training needs and disseminated the VEHDI Program Implementation Guide.
- Parent letters were translated into six languages. The EHDI awareness poster for parents was translated into Spanish and distributed to local health departments and health care providers.
- VEHDI staff promoted their services at medical professional conferences with a program display that outlined roles and responsibilities of the primary care providers. Staff provided copies of the parent posters as well as penlights and magnets featuring the program name and toll-free number.
- VEHDI staff continue to participate with the CDC Program Evaluation Project that is focusing on the problem of infants lost to follow up. Virginia is one of five states chosen to participate in this project. Activities include conducting focus groups, maternal interviews, and hospital exit surveys in order to examine barriers and factors that contribute to loss or delay to follow up.

2004 Program Goals:

- Update list of approved providers of audiological services.
- Revise the form for reporting follow-up audiological screening and assessment.
- Conduct a survey of Virginia-licensed audiologists regarding hearing aids for children.
- Establish a bank of hearing aids to loan to children under the age of 3.
- Improve telephone communication access for non English-speaking families.
- Continue to train and educate hospital staff, audiologists, early intervention providers, and primary medical care providers.

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For more information, Please visit our Web site at www.vahealth.org/hearing

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