

Report

Universal Newborn Hearing Screening in Washington State

February 2007



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Report

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Executive Summary

In 2005, 82,625 infants were born in Washington State. Based on national estimates, 82-247 of these infants were born deaf or hard of hearing. Without early identification and intervention services by 6 months of age, infants who are deaf or hard of hearing may suffer delays in language development leading to permanent cognitive and social delays.

Early identification of infants with hearing loss begins at birthing hospitals with newborn hearing screening. Approximately 80,000 (98%) infants in Washington are born in hospitals. According to annual Department of Health (DOH) surveys, Washington State hospitals reported an increase in the statewide hearing screen rate from 88% in 2004 to 94% in 2005. Of the nearly 6% of infants born at hospitals who did not receive a hearing screen in 2005, 5-14 would be expected to have hearing loss.

Infants identified with hearing loss after 6 months of age are at increased risk for language, cognitive, and social delays and may require additional services and support. Studies indicate that early identification of, and interventions for, hearing loss result in cost savings in educational settings.

Collaborative efforts to support voluntary Universal Newborn Hearing Screening (UNHS) continue to improve hospital-based programs around the state. In 2003, 50 out of 72 birthing hospitals reported having UNHS programs. By December of 2005, 68 of the 69 birthing hospitals had programs (note: some hospitals stopped providing delivery services). As of November 2006, all Washington birthing hospitals have UNHS programs.

DOH's tracking and surveillance system, known as the Early Hearing loss Detection, Diagnosis, and Intervention (EHDDI) system, follows infants born in Washington to verify that they receive a hearing screen by 1 month of age and diagnostic evaluation, if needed, by 3 months of age. All 66 non-military birthing hospitals in Washington voluntarily report newborn hearing screening results to DOH. DOH provides follow up services for these hospitals. In addition, DOH collects diagnostic information from 10 pediatric audiology clinics by a Web-based reporting system. Forty-five other audiology clinics fax or provide over-the-phone visit summaries for patients referred to the clinics after failing their newborn hearing screens.

In 2005, DOH followed 67,080 infants using the EHDDI tracking and surveillance system. Analysis of reported hearing screen data and follow-up outcomes for these infants indicate that approximately 94% of infants received a hearing screen. Through this system, DOH confirmed the diagnosis of some degree of hearing loss in 147 of these infants. This is within the expected range for this population.

Statewide efforts to improve UNHS are working. However, more analyses and additional efforts are needed to determine the effectiveness and sustainability of these voluntary programs. Topics needing additional attention include: evaluation of infants requiring audiologic assessment, efficacy of providing follow-up services for at-risk infants, improving early-intervention services, and identifying sustainable funding for the EHDDI program.

Background Information

Congenital hearing loss has a relatively high prevalence compared to other conditions screened for at birth such as Phenylketonuria (PKU), which occurs in 1 per 15,000 infants.ⁱ According to national estimates, 1-3 of every 1000 infants are born deaf or hard of hearing.ⁱⁱ
iii iv v

Approximately 80,000 infants are born in Washington State each year.^{vi} Based on the national frequency of early hearing loss, it is expected that between 80 and 240 infants are born with hearing loss in Washington State annually. Studies show that identifying these infants early and enrolling them into intervention services by 6 months of age contributes to age-appropriate language and cognitive development.^{vii viii ix} Newborn hearing screening is the first step towards this early identification of infants with hearing loss. Without newborn hearing screening, the average age at the time of identified hearing loss is between ages 12 to 25 months.^x

Newborn hearing screening is typically performed at the hospital shortly after birth. The procedure may consist of Otoacoustic Emissions (a measure of middle ear function), Auditory Brainstem Response (a measure of the brain's response to sound), or a combination of both tests. Infants who do not pass the newborn hearing screen are referred to a pediatric audiologist to establish a diagnosis through a thorough physiologic and behavioral evaluation. For infants diagnosed with hearing loss, there are many management and long-term intervention services to consider.

National recommendations set forth by the Joint Committee on Infant Hearing¹ in 2000 are (1) all newborns will be screened for hearing loss before 1 month of age, preferably before hospital discharge, (2) all infants who screen positive will have a diagnostic audiologic evaluation before 3 months of age and, (3) all infants identified with a hearing loss will receive appropriate early intervention services before 6 months of age. These are known as the national "1-3-6 goals."^{xi} The Department of Health's (DOH) Early Hearing loss Detection, Diagnosis, and Intervention (EHDDI) program strives to meet these national goals.

¹ The Joint Committee on Infant Hearing is composed of representatives from the American Academy of Audiology, the American Academy of Otolaryngology-Head and Neck Surgery, American Academy of Pediatrics, American Speech Language Hearing Association, Council on Education for the Deaf, and Directors of Speech and Hearing Programs in State Health and Welfare Agencies. The primary function of this committee is to make recommendations concerning the early identification of children with, or at-risk for hearing loss, as well as newborn hearing screening.

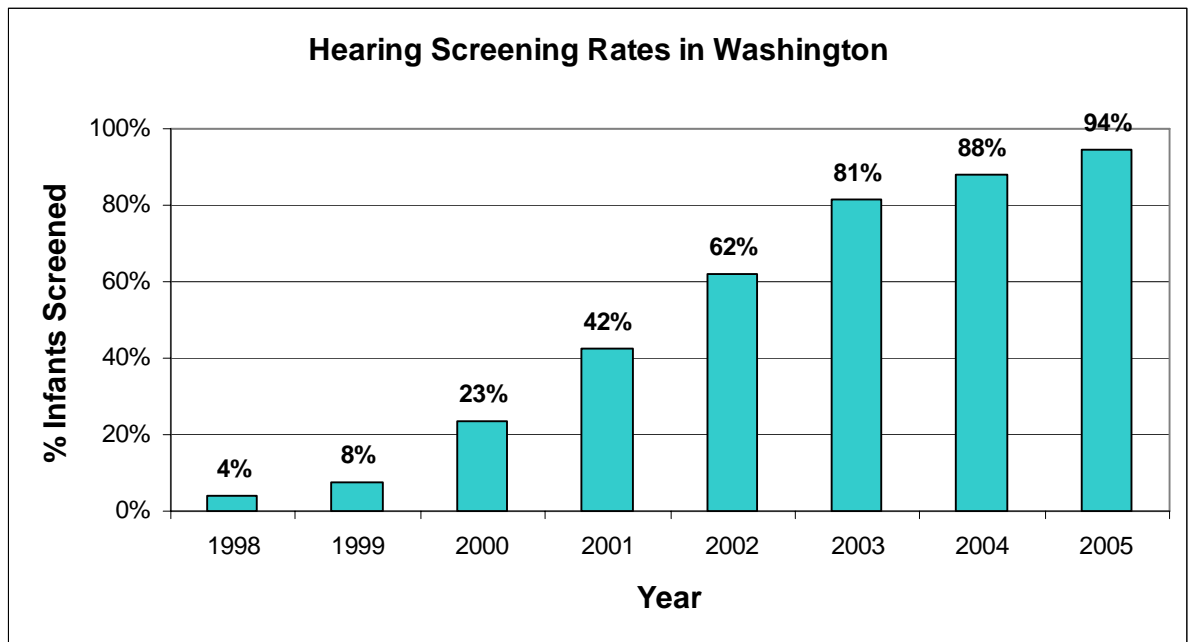
Current Hearing Screening Rates in Washington

In 2005, 82,625 infants were born in Washington birthing hospitals. Early identification of infants with hearing loss begins at birthing hospitals with newborn hearing screening.

Hearing screening has been performed in Washington for many years. However, annual hospital hearing screen rates in Washington have only been collected by DOH since 1998. Hearing screening information was collected via phone and mail surveys from birthing hospitals in Washington through 2005. In 2005, 65 of the 69 birthing hospitals responded to the survey, a copy is provided in **Appendix A**. For hospitals that did not complete the survey, screen rates were estimated using hospital birth rosters and data in the EHDDI tracking and surveillance system.

The annual hearing screen rates from 1998 to 2005 are presented in **Figure 1**. These data reflect the total number of reported infants born at all Washington birthing hospitals who received a newborn hearing screen. The steady increase in hearing screen rates since 1998 is a product of both national and state efforts to identify all infants with hearing loss as soon as possible. Many of these efforts in Washington are described in the following section.

Figure 1



Approximately 4,800 (6%) infants born at hospitals in Washington did not receive a hearing screen in 2005. According to national prevalence estimates, 5-14 of these infants may have a hearing loss. The economic cost of failing to identify infants who are deaf or hard of hearing and enroll them into intervention is still being defined. Recent findings have shown that health, social, and broader societal costs in a given year were lower by 15% in areas with UNHS programs.^{xiii} While the difference was not statistically significant, it does reflect the influence of early identification in a community. Infants identified after 6 months of age are

at increased risk for language, cognitive, and social delays that may require additional services and support.^{xiii} A formal public hearing and literature review (Sunrise Review) conducted by DOH in 2002 found that the fiscal benefits of UNHS programs are not seen in the health care system. However, societal and special education savings are significant.^{xiv}

Collaborative Efforts Supporting Universal Newborn Hearing Screening in Washington:

Hospital-based UNHS programs seek to screen all infants born at their facilities for hearing loss. The efforts to support and sustain these voluntary UNHS programs are collaborative and multi-faceted. Below are some of the groups in Washington involved in these efforts and their contributions to UNHS.

Washington State Birthing Hospitals

UNHS programs are located within individual birthing hospitals. At the end of 2006, all Washington birthing hospitals had implemented UNHS programs. Hospital staff are responsible for nearly all aspects of UNHS program development and maintenance. This includes:

- determining their screening protocol from options shared by DOH.
- determining procedures.
- training screening staff.
- recording and reporting results.
- financing the program.
- obtaining and caring for screening equipment.
- communicating with parents, DOH and care providers.

All but the three military hospital UNHS programs are coordinating efforts with DOH to collect and report hearing screen results. Military hospitals (approximately 3000 births) in Washington use Oregon's newborn screening laboratory and follow-up services for metabolic screening. Since DOH's newborn hearing screening tracking and surveillance system is integrated with Washington State's metabolic screening program, coordination between military hospitals and the DOH is not feasible at this time.

Washington State Hospital Association

The Washington State Hospital Association (WSHA) provides leadership, advocacy, and support to Washington hospitals. The WSHA plays a critical role in encouraging hospitals to establish and maintain voluntary UNHS programs.

Children's Hospital and Regional Medical Center (CHRMC)

DOH contracts with CHRMC audiologists and staff to provide on-going technical assistance to hospital based UNHS programs. CHRMC makes annual site visits to hospitals, conducts annual UNHS manager trainings, and works with DOH staff to develop and distribute professional and parent educational materials.

Audiologists

Audiologists provide the critical step to identifying those infants who are truly deaf or hard of hearing. They perform diagnostic evaluations on infants who do not pass their hearing screen. Audiologists also assist DOH in reviewing proper protocols in hearing screening and diagnostic evaluation. These are outlined in Appendix B and Appendix C. Finally, audiologists work with DOH to collect and report diagnostic results through a secure Web-based extension of DOH's tracking and surveillance system.

The Department of Health

DOH established the EHDDI program to help coordinate a statewide effort to improve and support screening, diagnostic, and early-intervention services for infants born with hearing loss, or increased risk for late onset hearing loss in childhood. Most importantly, DOH developed the EHDDI tracking and surveillance system, which follows infants from hearing screening through diagnostic evaluation. This surveillance system is discussed in further detail in the next section. In addition, DOH works with its partners described above to promote quality UNHS programs. DOH also works with, other government and private partners such as the DOH Children with Special Health Care Needs program, the Department of Social and Health Services Office of the Deaf and Hard of Hearing, and the Infant Toddler Early Intervention Program, MSR Northwest, and the Lion's Club, to maximize and improve coordination of services.

Status of the Department of Health's System for Monitoring, Assisting, and Evaluating Universal Newborn Hearing Screening

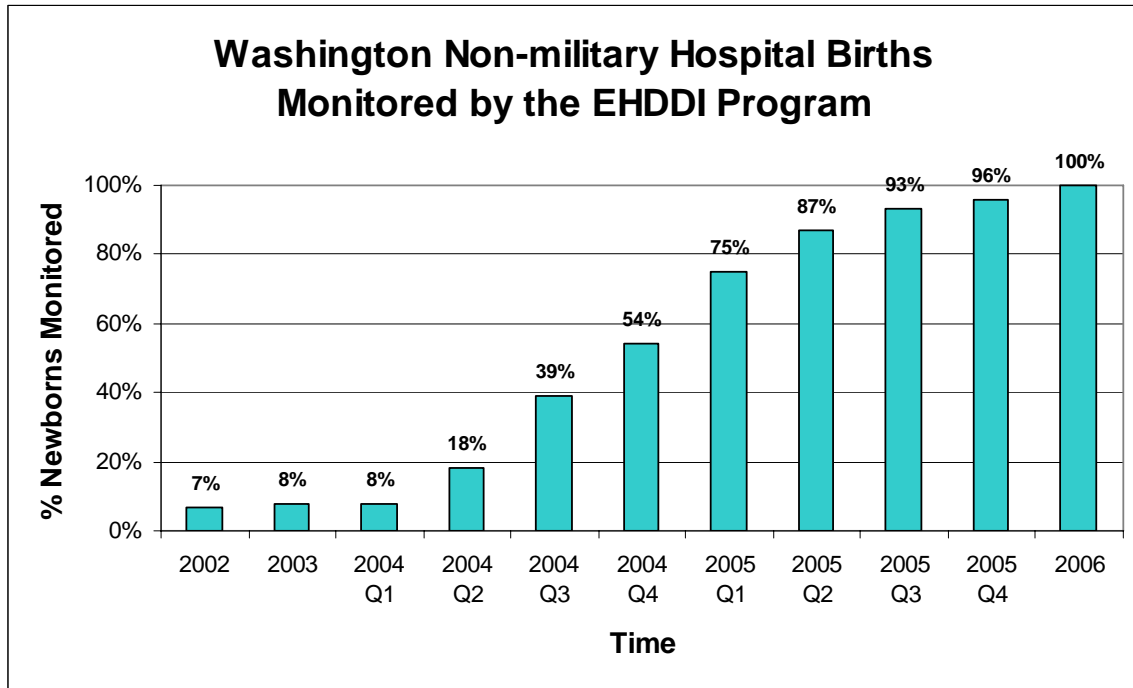
In 2000, DOH received a Cooperative Agreement from the Centers for Disease Control and Prevention as well as a grant from the Health Resources and Services Administration to establish the EHDDI program. DOH also received general fund state dollars for the 2003-2005 biennium to assist with program development. The goals of the EHDDI program are consistent with the national 1-3-6 plan, which states that all newborns be screened for hearing loss before 1 month of age (preferably before hospital discharge), all infants who screen positive have a diagnostic audiologic evaluation before 3 months of age and, finally, all infants identified with a hearing loss receive appropriate early intervention services before 6 months of age. Ultimately, the EHDDI program aims to improve and support screening, diagnostic, and early-intervention services for infants born with hearing loss, or at an increased risk for late onset hearing loss in childhood.

In the past five years, one of the accomplishments of the EHDDI program has been to develop a tracking and surveillance system. This system supports hospital-based UNHS programs by (1) monitoring whether every infant receives a hearing screen, (2) assisting in making recommendations for timely follow-up care through diagnostic evaluation, and (3) providing quality assessment and control through regular hospital and statewide data analysis.

Hospital Participation with the EHDDI Program

In 2002, the EHDDI program initiated its tracking and surveillance system with monitoring infants born at five pilot hospitals. By the end of 2005, hospital participation increased to 65 of the 66 non-military birthing hospitals reporting hearing screening results to DOH. Figure 2 illustrates the increase in the percent of newborns monitored by the EHDDI program for receiving hearing screens and appropriate follow-up care. Time increments reflect quarters (e.g. Q1 = January – March), for 2004 and 2005 to illustrate significant effort to incorporate data from all of the non-military birthing hospitals into the EHDDI system. For further information specific to follow-up actions, please refer to Appendix D.

Figure 2.



Monitoring Whether Every Infant Receives a Hearing Screen

The EHDDI tracking and surveillance system compares live birth records with hearing screen results to monitor whether every child has received a hearing screen. Results of this comparison for 2005 are shown in Table 1. Primary care physicians of infants who did not receive a hearing screen are identified and follow-up actions are initiated to help ensure a hearing screen is performed by 1 month of age.

Table 1

Infant Hearing Screen Records 2005		
Infants with a Hearing Screen Record (a)	63,485	94.6%
Infants without Hearing Screen Records (b)	2989	4.5%
Parents refused (c)	606	<1%
Total Live Births (d)	67,080	100%

- (a) Hearing screen record was reported via the revised blood spot card
- (b) Infants without records were either missed or results were not reported
- (c) Parental refusal for hearing screening indicated on revised blood spot card
- (d) Total live births excludes infants who die, at or shortly after birth, at-home births, and births occurring at hospitals not participating in the EHDDI program

Assisting in Appropriate and Timely Follow-up Care

Reported hearing screen results or missed hearing screens generate a series of follow-up actions to ensure that timely follow-up care is provided through diagnostic evaluation. The EHDDI program staff uses letters, faxes, and phone calls to inform infants' primary care providers about hearing screen results and recommendations for additional hearing screening or evaluation. The follow-up outcomes for all 2005 births (67,080) in the system are detailed in Table 2.

For the 680 infants referred for additional audiological evaluation, 10 out of 55 audiology clinics reported diagnostic information through a secure Web-based extension of the system. The available diagnostic outcomes for infants who did not pass their hearing screen and were referred for additional audiological evaluation are reported in Table 3.

Of note, Table 3 includes the outcome results for some infants that were not recorded by DOH as having failed a hearing screen, but were still found to be referred for audiological evaluations. This may have occurred because the infant had one or more risk factors for late-onset hearing loss, was born at a hospital not participating with the EHDDI program at the time of birth, or the parent had additional concerns that brought the infant in for an evaluation. Therefore a total of 777 infants had a reported diagnostic outcome instead of the 680 reported on Table 2.

Based on the national incidence of early hearing loss of 1-3/1000 infants born deaf or hard of hearing, between 67 and 201 patients of the 67,080 patients followed by the EHDDI program during 2005 would be expected to have early hearing loss. The DOH EHDDI program identified 147 patients with confirmed hearing loss, which is within the expected range.

Table 2

Follow-up Outcomes 2005		
Definition of Outcome	Number of Infants	Percent of Infants
Infant passed hearing screen(a)	61,411	91.5%
Care provider shared recommendations for additional evaluation with infant's parents	2127	3.2%
Infant was lost to follow-up efforts(b)	798	1.2%
Infant was referred to an audiologist for further evaluation because of failed hearing screen(s)(c)	680	1.0%
Infant's parents refused further hearing evaluation	700	1.0%
Infant was referred to an audiologist for	1185	1.8%

further evaluation because of reported risk factors on modified blood spot card(d)		
Infant moved out of Washington State or away from location of primary care provider	94	<1%
Infant died during course of follow-up	85	<1%
TOTAL	67,080	100%

- a) Received a normal screening result on either first or second newborn hearing screen and had no risk factors for late-onset hearing loss
- b) Status of infant is considered 'lost', either because DOH could not identify current care provider or provider could not contact infant's parents
- c) The Follow-up Outcomes for these infants are included in **Table 3**
- d) See **Table 4** for definition of risk factors reported on the modified blood spot card

Table 3

Diagnostic Outcomes for Infants Referred to Audiologists - 2005(a)		
Definition of Final Disposition	Number of Infants	Percent of Infants
Patient was found to have normal hearing	368	47.4%
Hearing loss was confirmed	147	18.9%
Outcome is unknown (b)	215	27.7%
Patient's evaluation was inconclusive	47	6.0%
TOTAL	777(c)	100%

- a) Diagnostic outcomes were gathered through the Web-based reporting system as well as phone calls made by the EHDDI staff
- b) Patient did not go to appointment, did not return for follow-up diagnostic appointment, or place of referral was not found by DOH
- c) Includes infants referred whom the DOH was tracking because of failed hearing screen(s) and infants DOH became aware of by being notified of audiologic evaluation by audiology clinic

In addition to infants born deaf or hard of hearing, the EHDDI program follows infants at-risk for developing late-onset or progressive hearing loss. Specifically, the system identifies these infants when any of four risk factors are reported. See **Table 4** for definitions of these risk factors. Follow-up efforts carried out by the EHDDI program staff encourage care providers to refer at-risk infants to an audiologist for an evaluation every six months until age 3 years.

Of the 67,080 patients followed in 2005, 1185 (1.8%) patients were found to have one or more of these risk factors but passed their newborn hearing screens. The EHDDI program was able to determine that the recommendations for additional audiologic evaluation was

given to the parent by the primary care provider in 716 (60.4%) of the cases. However, only 19 of these 716 patients (26.5%) had a recorded audiologic evaluation in the EHDDI tracking and surveillance system. This is most likely a reporting issue due to audiologists failing to enter data for at-risk infants.

Table 4

Risk Factors for Early Hearing loss	
Risk Factor	Definition
Syndromic Stigmata	<i>Stigmata or other finding associated with a syndrome known to include sensorineural and/or conductive hearing loss</i>
Family History	<i>A family history of permanent childhood sensorineural hearing loss</i>
Craniofacial Anomalies	<i>Morphological abnormalities including of the pinna and ear canal</i>
Maternal Illness	<i>In-utero infections such as cytomegalovirus, herpes, toxoplasmosis, or rubella</i>

Providing Quality Assessment and Control

The EHDDI program assists statewide UNHS efforts by providing hospitals with regular reports to assist in program performance evaluation. This evaluation is particularly important given the wide variety of UNHS program protocols in Washington State. In addition, the EHDDI program routinely conducts internal evaluations to assess the effectiveness of the system. The evaluations assess whether the letters, phone calls and faxes are received by providers in a timely fashion, the information provided to primary care providers is adequate, hospitals are satisfied with the evaluation information supplied to them, etc. Evaluations are accomplished through regular assessment of data collection methods, protocol revisions, technical upgrades, data analysis and other methods.

Ongoing Issues Related to Universal Newborn Hearing Screening in Washington

Identifying Sustainable Funding for Newborn Hearing Screening

The DOH EHDDI program and the follow-up services it provides are predominately funded by federal grants from the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC). An additional \$125,000 per year comes from general state funds, which are expected to continue through June of 2007. The CDC grant period runs through June 2008, and HRSA grant period runs through August 2008. However, federal grant funding is awarded one year at a time and is not guaranteed for the entirety of the grant period. Maintaining the program will require identifying ongoing funding to support the program.

Assist hospitals in continuous quality improvement efforts

Hospital based UNHS programs will not succeed unless they have management support and ongoing quality assurance. High false positive rates lead to a high number of patient referrals to audiologic evaluation. In turn this leads to increased parental anxiety and lower physician confidence in screening results. This can result in decreased compliance with recommended follow-up actions for newborns who have failed their hearing screens and at-risk infants. While 95% of newborns in 2005 received initial hearing screens prior to hospital discharge, high referral rates on initial screens remain a problem since they undermine the local physician's and parent's confidence in the screening itself and may deter families from pursuing recommended re-screens or audiologic evaluations. The average referral rate in Washington State in 2005 was 16.4% on initial screens, which is two times what is recommended. Currently, the EHDDI program contracts with an audiologist to provide ongoing technical assistance to hospital based UNHS programs. Annual coordinator's meetings are also held to work with hospital screening coordinators to decrease UNHS program issues. However, new strategies need to be developed to support and encourage hospitals to improve quality assurance and lower referral rates on initial screens.

Improve reporting to DOH by audiologists

Only 72% of infants who do not pass their hearing screens receive the recommended audiologic evaluations. An Attorney General's opinion states that DOH does not have the authority to contact parents regarding their babies' newborn hearing screening results and recommended follow-up since hearing screening is voluntary. This places the responsibility of notification and follow-up on health care providers. Further work is needed to identify ways to ensure that at-risk infants receive audiologic evaluations and that the diagnostic outcomes are reported to DOH.

Improve abilities and access to trained Early Intervention providers

The ultimate goal of UNHS programs and early diagnosis is to ensure infants who are deaf or hard of hearing receive timely intervention services and management to prevent delays in language and cognitive development. Currently, there is no statewide system to ensure infants receive intervention services following diagnosis. Furthermore, very few early intervention providers have the understanding or skills to work with families of infants with hearing loss. A focus of the EHDDI program in the coming year is to increase reporting of referrals to intervention services by audiologists after a diagnosis of hearing loss.

Government and community partners from around the state continue to develop and promote appropriate intervention services and support for infants who are deaf or hard of hearing and their families. For the past three years, DOH has contracted with Washington Sensory Disabilities Services to implement a training plan for early intervention service providers. The training augments providers' skills in working specifically with children who are deaf or hard of hearing. To date, providers in 17 counties have received training, and an additional eight counties are participating this year. Future plans include ongoing outreach and education for early intervention service providers.

DOH has received anecdotal reports of growing waiting lists for children to get into programs serving children aged birth to 3 years who have hearing loss. Providers attributed this trend to an increase in children who are identified early as having hearing loss: they believe more families are seeking services, and children receive services for a longer period of time due to earlier identification. DOH plans to investigate these reports in 2007 by surveying early intervention programs across the state.

Additional Resources

Alexander Graham Bell Association for the Deaf and Hard of Hearing (AGBell): AGBell is an international membership organization and resource center on hearing loss and spoken language approaches and related issues. AGBell publishes and distributes books, brochures, instructional materials, videos, CDs, and audiocassettes related to hearing loss and provides financial aid for mainstreamed, auditory-based education opportunities. **www.agbell.org**

American Academy of Audiology (AAA): is a professional organization dedicated to providing quality hearing care to the public. They provide consumer and professional resources related to hearing care. **www.audiology.org**

American Academy of Pediatrics (AAP): Provides information, alerts, and resources related to the physical, mental, and social health of infants, children, adolescents, and young adults. *Pediatrics* is an online publication of the American Academy of Pediatrics journal. The following is an article from one of their publications: *Universal Newborn Hearing Screenings: A Three Year Experience*. **www.aap.org**

American Speech-Language-Hearing Association (ASHA): Provides news, a resource center, and continuing education in the human communication field. **www.asha.org**

Boys Town National Research Hospital The below website was developed by Audiologists, Speech-Language Pathologists, Teachers of the Deaf, Geneticists, Doctors and Parents of Deaf and Hard of Hearing Children at the. This site includes information about infant hearing loss, how the ear works, family issues and some available intervention options. **www.babyhearing.org**

Centers for Disease Control & Prevention (CDC) Early Hearing loss Detection and Intervention (EHDI) Program: Promotes helping children to develop and reach their full potential, through early hearing loss detection and intervention. Collaborates with federal, national, and state agencies and organizations in assisting states and territories to develop and implement EHDI programs. **www.cdc.gov/ncbddd/ehdi**

Children's Hospital & Regional Medical Center (CHRMC): offers programs, lectures, and workshops focusing on audiology, hearing screening technology, communication skills, and hearing loss in children. **www.newborn-hearing-screening.org**

Health Resource Services Administration (HRSA) Maternal and Child Health Bureau: A federal agency that administers the Universal Newborn Hearing Screening program, which awards grants to states. **<http://mchb.hrsa.gov/programs/genetics/hearingscreen>**

March of Dimes Washington State Chapter: The March of Dimes Birth Defects Foundation works to improve the health of babies by preventing birth defects and infant mortality. They do this by funding programs of community services, advocacy, research, and education. **www.marchofdimes.com/washington**

National Center for Hearing Assessment and Management (NCHAM): The goal of the National Center for Hearing Assessment and Management at Utah State University is to ensure that all infants (newborns) and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention. **www.infantheating.org**

Washington Sensory Disabilities Services (WSDS): provides information, training, technical assistance, and resources to families and educators statewide regarding individuals from birth to 21 years of age with sensory disabilities - students who are deaf, hard of hearing, visually impaired, blind, or deaf-blind. **www.wsdsonline.org**

Washington State Department of Social and Health Services (DSHS) Infant Toddler Early Intervention Program (ITEIP): Early intervention in Washington State is a collection of services families may need for their infants or toddlers with disabilities. Services include workshops, conferences, and information on infant/toddler development. Family Resource Coordinators (FRCs) offer assistance to families with children who are deaf or hard of hearing. **www1.dshs.wa.gov/iteip**

Washington State Office of the Deaf and Hard of Hearing (ODHH): Provides services to the deaf, hard of hearing and deaf-blind communities throughout Washington State. ODHH contracts with six community service centers located in Seattle, Tacoma, Vancouver, Pasco, Spokane, and Bellingham to provide communication access advocacy, sign language interpreter information, workshops, information and referral, counseling, outreach and independent living support services to clients and their families. **<http://www1.dshs.wa.gov/hrsa/odhh>**

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