Legislative Report

Task Force on Early Hearing Loss Detection, Diagnosis and Intervention (EHDDI)

November 1998

Community and Family Health

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Task Force Background

In March of 1998, a Resolution was passed in the Washington State House of Representatives recognizing the importance of hearing screening within the first three months of life for all children born in Washington. Prior to the passing of this resolution, the Department of Health (DOH) commissioned a statewide needs assessment on early hearing loss detection, diagnosis and intervention (EHDDI), that was completed in January, 1998.

Subsequent to the passing of this resolution, Representative Steve Conway of the House Health Committee referred the issue to DOH for further exploration, and requested a report be prepared by December 1, 1998. DOH responded by convening a task force comprised of the individuals listed on page 3 of this report.

At its initial meeting in July of 1998, the Early Hearing Loss Detection, Diagnosis and Intervention (EHDDI) Task Force identified its primary task as identifying the environment needed in Washington State for the successful development and implementation of early hearing loss detection, diagnosis and intervention programs.

This EHDDI Task Force report outlines key elements, and identifies known best practices for EHDDI. In addition, it addresses the importance of follow-up and early intervention services for infants identified with hearing loss, recognizing the fact that identification is just the beginning of a process to help affected children and their families achieve their fullest potential.

Executive Summary

Statement of the Problem

In 1998, between 115 and 232 Washington State children will be born with significant hearing loss. More than half will not be diagnosed with hearing loss until after the age of two.

The time between birth and three years of age is the most important period for language development. For most children with hearing loss, this critical window of development is closed by the time their hearing loss is detected. Unrecoverable developmental losses occur when hearing loss is identified later than six months of age.[1,2,3,4,5] Optimal outcomes for affected children and their families occur with early identification and intervention, preferably before three months of age.

Undetected congenital hearing loss significantly impedes speech, language, cognitive and social development.[6] Recent data indicate that regardless of the degree of hearing loss, children whose hearing loss is diagnosed and who begin early intervention before six months of age have better language development than those who begin intervention after six months of age.[7] The positive effects were found at each test age (12, 18, 24, 36 and 48 months), regardless of communication mode (i.e., Sign Language, Total Communication or Oral), gender, ethnicity, or socioeconomic status.

Initiating Early Hearing Loss Detection, Diagnosis and Intervention

The Task Force reviewed research that has demonstrated the value of early hearing loss detection, diagnosis and intervention.[8] Advances in technology, and increased local and national interest create an opportunity to consider performing hearing screening on all newborns. The implementation of hearing screening for newborns, would be one part of early hearing loss detection, diagnosis and intervention (EHDDI) in Washington State.

Experience from across the United States[9, 10] shows that successful EHDDI efforts include the following critical components:

- Detection: Screening of all infants for hearing loss by three months of age. Screening should occur at the time of birth prior to hospital discharge, with coordination to screen non-hospital births by three months of age.
- Diagnosis: Provision of appropriate audiologic evaluation and diagnosis by six months of age for all infants who fail the screen. Tracking mechanisms should be in place to ensure that children who screen positive are referred for and receive appropriate diagnostic services.

- Intervention: Initiation of appropriate intervention immediately after diagnosis and no later than six months of age for affected infants. A system of care and monitoring that ensures children are referred for and receive appropriate intervention services must be in place.
- All children continue to receive periodic hearing evaluation as part of routine, well child check-ups, with their primary care provider, with intervention beginning at the time a diagnosis of hearing loss is made.

Formation of the EHDDI Task Force

In recognition of these findings, a Washington State Resolution was passed in early 1998. The Legislature requested that the Department of Health (DOH) develop recommendations regarding early hearing loss detection, diagnosis and intervention. DOH brought together the EHDDI Task Force, whose membership is listed on page 3, for that purpose.

EHDDI Task Force Recommendations

The EHDDI Task Force recommends that by the year 2001 every baby born in Washington State be screened for hearing loss by the age of 3 months, using objective test technology. The EHDDI Task Force further recommends that children who fail the hearing screening receive appropriate diagnostic testing no later than 6 months of age, and that intervention begin at the time a diagnosis of hearing loss is made.

"The future of a child born with a significant hearing impairment depends to a very large degree on early identification, followed by immediate and appropriate intervention. If hearing impaired children are not identified early, it is difficult, if not impossible, for many of them to acquire the fundamental language, social, and cognitive skills that provide the foundation for later schooling and success in society."

US Department of Health and Human Services

In order to accomplish this the Task Force recommends the following:

- Further study to: identify existing services in communities and/or gaps in services for children with hearing loss; and develop and provide necessary training, education, and coordination to ensure access to appropriate intervention services for children with hearing loss.
- The funding and implementation of EHDDI pilot projects in a variety of geographic and demographic settings that reflect the diversity of Washington State.
- The establishment of an EHDDI Implementation Advisory Committee to guide the selection of birthing hospitals and surrounding communities for pilot projects, and provide oversight for the statewide implementation process.
- The development of collaborative efforts between state and local public and private organizations, agencies, and insurers to maximize existing and potential resources to implement and sustain EHDDI.

The following report provides additional information to support the development of these recommendations.

Occurrence of Hearing Loss in Infants in Washington

Hearing impairment is one of the most common major abnormalities present at birth.[11] Nationally, 1.5 to 3 of every 1000 children will be born with a hearing loss significant enough to impede cognitive, language, social and educational development.[12,13,14] Based on 77,161 resident births in 1997, between 115 and 232 Washington State children will be born this year with significant hearing loss. Hearing loss occurs more frequently than any of the conditions which newborns are currently screened for in this state, such as Phenylketonuria (PKU) or sickle cell disease.

Advances and Opportunities in Early Hearing Loss Detection, Diagnosis and Intervention

Early brain development and neural pathway formation is critical to an infant's life long learning ability.[15] Communication plays a critical role in this process and underscores the importance of early hearing loss detection, diagnosis and intervention to promote early communication development.[16]

Twenty years' experience and data from 120 universal hearing screening programs have proven the effectiveness of early hearing loss detection, diagnosis and intervention or EHDDI.[17] This research clearly demonstrates that early identification, diagnosis and intervention of hearing loss is necessary in order for children with hearing loss to develop age-appropriate language skills similar to those of children with full hearing capability.[18] Early intervention promotes the development of language and communication skills, enhancing psychological and sociological growth and improving a child's ability to learn.[19]

A recent article by Yoshinaga-Itano published in *Pediatrics* (November, 1998) provides an overview of research on early hearing loss and identification. "Children identified (with hearing loss) between birth and six months of age with immediate intervention (e.g. Amplification, family centered programs) have significantly higher developmental function that those with delayed identification in:

- Expressive language
- Expressive vocabulary
- Communicative gestures
- Comprehension
- Number of consonants and vowels.

Communicative development among children identified with

hearing loss between birth and six months of age and receiving immediate and appropriate intervention is equivalent to that of normal hearing peers."[20]

With intervention, children with hearing loss can reach communicative development equivalent to normal hearing children and can reduce their need for future special education services.[21] A 1988 study by the U.S. Department of Education[22] showed the following cost comparisons by classroom type:

- $3,383/year/child in a regular classroom,
- $9689/year/child in a self-contained classroom,
- $35,780/year/child in a residential setting.

Potential Costs of Not Providing EHDDI

Without early identification and intervention, children with hearing loss experience delays in the acquisition of communication skills, and other developmental delays that put them at risk for lifelong disadvantages. According to DSHS, in Washington State 65% of the deaf population lives at or below the federal poverty level.[23] The unemployment rate for deaf high school graduates is twice that of the hearing population and profound deafness produces an estimated national loss of income of approximately $2.5 billion dollars annually.[24]

Best Practices in EHDDI

Early hearing loss detection, diagnosis and intervention is composed of the following components:

- Screening of all infants for hearing loss by three months of age using objective technology. Screening should occur at the time of birth prior to hospital discharge, with coordination to screen non-hospital births.

- Provision of appropriate audiologic evaluation and diagnosis by six months of age for all infants who fail the screen. A Tracking system is used to ensure diagnostic evaluation is provided.

- Initiation of appropriate interventions at diagnosis, and no later than six months of age for infants with hearing loss. For children identified later in life, intervention should start at the time of diagnosis. Monitoring is important to ensure children are referred for and begin intervention services.

- Intervention should include family centered programs,

amplification fitting and initiation of communication methodology.

- Programs should provide parents with information about options and all communication models available. Because a significant proportion of congenital hearing loss is hereditary, parents should be informed of the availability of genetic counseling and evaluation.
- All children continue to receive periodic hearing evaluation as part of routine well-child check-ups with their primary care providers.

Availability and Cost of Testing Technology

Effective, reliable, affordable testing using objective procedures is now available. Auditory brainstem response (ABR) and evoked otoacoustic emissions (EOAEs) technology has provided the means to effectively, efficiently screen for hearing loss. A broad range of trained personnel can perform screening.[25,26,27] A recent study published in the journal *Pediatrics* demonstrates that advances in newborn hearing screening technology have improved hearing testing accuracy.[28] With this technology, two to six percent of newborns tested will not pass the screen, and will require further testing.

The average per child cost of a hearing screening is between $18 and $33.[29,30] Insurance coverage for hearing screening varies from state to state. A Colorado model for cost predictions based on subsequent intervention savings has shown a recovery of all screening costs after only 10 years of screening all newborns. This is accomplished through the prevention of delayed diagnosis, intensive language development interventions, and specialized training.[31]

Strong Professional Endorsements

Many professional and community groups have recognized the importance of the advances in hearing screening, early brain development research and the value of early intervention. The 1993 NIH Consensus Statement on universal newborn hearing screening set the stage for much subsequent activity.[32] The US Department of Health and Human Services Healthy People 2000 initiative includes an objective (#17.6) which states, "By the year 2000, 90% of all children with significant hearing impairments will be identified by 12 months of age." The Maternal Child Health Bureau, recognizes the importance of early hearing loss detection, and has developed a national performance measure for every state, requiring them to report, “the percentage of newborns screened for hearing loss prior to hospital discharge.”

Professional groups endorsing EHDDI include:

- The Joint Committee on Infant Hearing (1994) which includes:
  - The American Speech-Language-Hearing Association
  - The American Academy of Otolaryngology
  - The American Academy of Audiology
  - The American Academy of Pediatrics
  - The Directors of Speech and Hearing Programs in State Health and Welfare Agencies
- The National Institutes of Health Consensus Committee
- The National Institute on Deafness and other Communication Disorders
- The Surgeon General
- The Centers for Disease Control and Prevention
- The Federal Bureau of Maternal and Child Health
- The Alexander Graham Bell Association for the Deaf
- Self Help for the Hard of Hearing People
- The National Society of Genetic Counselors

Eight states have passed legislative language that mandates EHDDI, and a federal bill is pending action in Washington D.C. Seventeen states have pledged to implement universal newborn hearing screening by the year 2000 with the support of the Federal Maternal Child Health Bureau. Additionally, many states have supported volunteer screening programs. Reviews of these state programs are well documented in the literature and will provide a wealth of information for Washington's efforts.[33]

Local Interest in EHDDI

There is increasing local interest in communities across the state in the development of early hearing loss detection, diagnosis and intervention programs. A community-based effort in Spokane has been working on post discharge early hearing screening. Yakima Valley Memorial Hospital has recently begun to investigate the potential for including newborns, beyond those in their neonatal intensive care units for screening. Both sites already have testing equipment available. In Bellingham a community-based effort has identified existing resources and potential partners for creating an EHDDI program in their local hospital.

Current Detection and Diagnostic Practices in Washington State

In a 1997 survey of 86 hospitals for the Washington Universal Newborn Hearing Screening Needs Assessment, 81.5% reported that they do not currently do neonatal hearing screening/testing, and 74.5% expressed interest in a pilot program with technical support. The 18.5% of hospitals that reported doing neonatal hearing screening/testing were all located in metropolitan areas and screened only infants in the Neonatal Intensive Care Unit.[34] However, less than half of all children with hearing loss spend any time in neonatal intensive care units (NICU). Children are most frequently identified with hearing loss by their parents after age two.

Post neonatal objective screening is inconsistent across the state making early identification difficult. An effort in Spokane to screen infants and toddlers after hospital discharge met with extremely limited success, even when the screenings were offered at no charge. Barriers to post-hospital-discharge testing may include, but are not limited to:

- difficulty obtaining referrals from primary care providers for objective testing at specialists' offices,
- difficulty for new parents to include another outside outing to a different location,
- lack of provider awareness of the effectiveness of current screening and intervention technologies.

The average age of identification of hearing loss is 2 ½ years. In the Spokane area, a review of the charts of 68 children being served through the Children with Special Health Care Needs (CSHCN) Program revealed the average age for initial hearing aid fitting was 4 years and 9 months. Children in this group with multiple disabilities were fitted at an average of 8 years and 4 months.

Parents surveyed overwhelmingly supported the option of universal newborn hearing screening.[35]

Children with Unidentified Hearing Loss

In 1996 there were 234,894 children under age three in Washington. Projected incidence rates of 1.5 to 3 children per thousand with hearing loss, would suggest a minimum of 352 and as many as 705 children with significant hearing loss under the age of three in the state. In a survey conducted by the Office of the Superintendent of Public Instruction (OSPI) Statewide Project for Infants & Toddlers with Hearing and/or Vision Disabilities of all

programs in the state serving infants and toddlers for that same year, only 167 children with hearing loss were found. The fact that so few of the expected hearing loss affected children were found in these services could indicate that 53% to 76% of children with hearing loss remain undiagnosed or are not accessing these services for unknown reasons.

Current Intervention Services in Washington State

Existing intervention services, which may include children's communication groups and home-based sessions, family counseling and support groups, and/or sign language classes, are not uniformly available or accessible across the state. Families in the greater Seattle-Tacoma metropolitan area have access to a comprehensive menu of early intervention services. Comprehensive early intervention service options to meet the needs of young children with hearing loss are very limited and vary greatly throughout the state. Insurance coverage for needed services varies significantly as well.

The OSPI Statewide Project for Infants & Toddlers with Hearing and/or Vision Disabilities survey identified two programs providing comprehensive audiological, early childhood education and family support services to infants and toddlers with hearing loss and their families. One private agency in Seattle serves King County and south Snohomish County. The other program is funded by OSPI, and serves Western Washington. Because center-based services are provided only in Seattle, families living in outlying areas must travel to receive services, or rely on those services available to them locally. Several hospitals provide some of the needed services, but not the "menu of services" that represent "best practices" in the field (e.g., sign language classes, audiological testing and follow-up, hearing aid fitting, early intervention services including both children's communication groups and home-based sessions, family counseling and support groups).

Approximately 53% of the school districts in Washington offer special education programs to children under the age of three; two of these districts, Tacoma and Evergreen, provide birth-to-three services specifically for infants and toddlers with hearing loss and their families. Children with special needs are served through developmental disabilities centers, neuromuscular programs, regional genetic clinics, and other "generic" programs where personnel rarely have adequate training, skills, and experience to provide appropriate services to infants and toddlers with hearing loss and their families. Eligible children may receive early intervention services, including specialized services, through I.D.E.A., Part C.

Current Policy and Systems Environment in Washington: Strengths

There are a number of factors that could impact EDDHI implementation in Washington. As stated earlier, intervention services are not universally available. There are some existing programs and resources that can provide a starting point for EHDDI. Some of these include:

- A successful model for newborn screening exists in the state's Newborn Screening Program administered by the Department of Health.

- There are currently networks for serving children with disabilities throughout the state.

- In addition to the Washington State Legislative Resolution, HR 2923 Early Hearing Loss Detection, Diagnosis and Intervention Act of 1997 was introduced in the House of Representatives at the Federal level. The bill supported important elements of EHDDI including:
  - screening for all infants prior to hospital discharge,
  - diagnostic testing if hearing loss is suspected,
  - linkage with community system of early intervention, and
  - establishment of public policy for the early detection and intervention of newborns with hearing loss based on applied research and consultation of the pertinent public stakeholders.

ough the bill did not pass, it is likely to be reintroduced in the 106th Congress in 1999.

- Medicaid covers 42% of all births in Washington State. Other states have partnered with Medicaid as the impetus for EHDDI implementation.

- The state's pediatric tertiary care hospitals possess the expertise to provide EHDDI services, serving as a potential starting point for coordination of services.

Current Policy and Systems Environment in Washington: Barriers

The potential barriers to the implementation of effective EHDDI include:

- The need to ensure appropriate critical components of a screening program are in place, including sources for diagnostic confirmation and intervention services.
- Identifying funding for EHDDI.
- Many insurers, including Medicaid, do not currently allow parents to self-refer their children for hearing screening.
- Current hearing testing guidelines for EPSDT (Early Periodic Screening Diagnosis and Treatment) well-child checkups allow either subjective or objective testing. Subjective testing has proven less effective than objective testing in identifying hearing loss in the first three months of life.[36,37]
- Health insurers do not consistently consider hearing screening "medically necessary" and they may deny coverage. As a non-mandated benefit, there is no guarantee that insurers will cover the screening costs associated with EHDDI even if services are available.
- Many children in Washington State are uninsured.
- Although services exist for children with disabilities through a network of providers funded by IDEA Part C, State Title V Programs, and others, there are no guidelines for appropriate standards of service and not all providers are trained to provide services to very young children with hearing loss.
- Most insurers do not cover amplification and other intervention services for children with hearing loss. Medicaid does provide coverage for hearing aids, but current reimbursement rates are not sufficient to cover the cost of more technologically advanced devices.
- Because many pregnancies are covered by capitated managed care agreements, hospitals and physicians receive a set payment per pregnancy. Any increase in newborn screening fees would affect the cost of care , and it is not clear how the additional cost would be absorbed.

EHDDI Task Force Recommendations

The EHDDI Task Force has developed the following recommendations for the implementation of early hearing loss detection, diagnosis and intervention for all newborns in Washington State.

The EHDDI Task Force recommends that by the year 2001 every baby born in Washington State be screened for hearing loss by the age of 3 months, using objective technology. The EHDDI Task Force further recommends that children who fail the hearing screening receive appropriate diagnostic testing no later than 6 months of age, and that intervention begins at the time a diagnosis of hearing loss is made.

To accomplish this, the Task Force recommends the following:

- **Assurance of Intervention Services:**

Further study to: identify existing services in communities and/or gaps in services for children with hearing loss; and develop and provide necessary training, education, and coordination to ensure that children with hearing loss have access to appropriate intervention services.

- **Pilot Projects:**
  The funding and implementation of EHDDI pilot projects in a variety of geographic and demographic settings which reflect the diversity of Washington state will:
  - Utilize birthing hospitals and surrounding communities as pilot sites to test and refine best practices, for screening, diagnosis, intervention, data collection and quality assurance.
  - Develop models for service coordination.
  - Support needed professional awareness, education, training and technical assistance.

- **EHDDI Implementation Advisory Committee:**
  Convene an expert Advisory Committee comprised of executive and legislative representatives, consumers, medical, audiology, and educational experts. The establishment of an EHDDI Implementation Advisory Committee to guide the selection of birthing hospitals and surrounding communities for pilot projects, and the statewide implementation process.

  The Advisory Committee will:
  - Identify one state agency to staff the advisory

committee, coordinate and oversee the pilots and statewide implementation of EHDDI.

- Guide the development of best practices and standards for the three phases of EHDDI including screening, diagnosis and intervention services.
- Identify best practices for tracking, evaluation and data collection for EHDDI.
- Inform the professional and wider community of the value of EHDDI.

- **Collaboration:**
  Develop collaborative efforts between state and local public and private organizations, agencies and insurers to maximize existing and potential resources to implement and sustain EHDDI.
  - Develop interagency coordination of funding issues for EHDDI.
  - Maximize existing and potential resources for each of the three primary components (screening, diagnosis and intervention) through collaboration between state and local public and private organizations and agencies, including insurers, the Department of Health, Medical Assistance Administration, Department of Social and Health Services, the Office of the Superintendent of Public Instruction, early identification programs, local public health departments and districts, local school districts, March of Dimes, the United Way and others.
  - Apply for federal funds should they become available to:
    - facilitate the implementation of newborn hearing screening,
    - develop best practice guidelines for hearing screening, diagnosis, and intervention
    - coordinate intervention efforts
    - develop and implement necessary training
    - pursue other activities related to the development and implementation of Early Hearing Loss Detection, Diagnosis and Intervention in Washington State.

EHDDI Background and Implementation Resources

- Mehl, AL, Thompson, V, Newborn hearing screening: the great omission, Pediatrics; 101:1-6, January 1998.
- National Center for Hearing Assessment and Management, Utah State University, UT - implementation background materials, guidelines, checklists and resource information and be found on their website at http://www.usu.edu/~ncham where there is also a resource section. An overview of the issues and literature can be found at http://www.usu.edu/~ncham/cdc/cdc_index.html .
- Marion Downs National Center for Infant Hearing hosts an exten website at http://www.colorado.edu/slhs/mdnc/ that includes information on what other states are doing regarding EHDDI.

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