

Oregon's Early Hearing Detection and Intervention Program (EHDI): The First Fifteen Years (1989-2004)

Martin B. Lahr and Kenneth D. Rosenberg

Oregon Department of Human Services

Abstract

Following unsuccessful efforts in the early 1990's, using a "high-risk" registry to identify infants with hearing loss, and following the development of practical automated electrophysiologic technology to identify hearing loss in infants, community advocates and the Office of Family Health (OFH) lobbied to introduce universal newborn hearing screening in Oregon. In 1999, the Legislature adopted a compromise bill that mandated screening in all hospitals with more than 200 births annually. When the new law took effect, in July 2000, the proportion of infants screened rapidly rose from 25% to over 94%. In 2003, the Legislature added mandatory individual-level reporting and the OFH established a registry. With these essential elements now in place, a critical task is to ensure complete follow-up of infants failing newborn hearing screening with diagnostic testing and early intervention, if appropriate. Health promoters and educators will play a key role encouraging participation in the Early Hearing Detection and Intervention Program by health professionals and parents.

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Scope of the Problem

Permanent Congenital Hearing Loss (PCHL) is arguably the most common significant congenital anomaly (Mehl & Thomson, 1998). Severe-to-profound bilateral hearing loss is estimated to occur in 1-3 per 1000 newborns. (Parving, 1993; Watkin, Baldwin, & McEnery, 1991; White, Vohr, & Behrens, 1993). An additional one to three per 1000 may have a less severe or unilateral hearing loss; these may be of educational significance as well (Brookhouser, 1996; Brookhouser, Worthington, & Kelly, 1991).

With approximately 46,000 births per year, we estimate that 50-150 newborns with severe-to-profound bilateral hearing loss, and an equal number with mild-to-moderate bilateral or unilateral losses, are born in Oregon each year. Without newborn hearing screening, the average age of children identified with hearing loss is about 2.5 years (National Institutes of Health, 2003; Oregon Advisory Committee on the Universal Detection of Newborns with Hearing

Loss, 1998). Studies have shown that intervention delayed beyond 6-12 months of age results in very significant delays in the development of communication and language skills by age five (Moeller, 2000; Yoshinaga-Itano, Coulter, & Thomson, 2000; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998).

An Oregon Health Division (OHD) Center for Child and Family Health (CCFH) survey of hospitals found that, as of July 1999, less than 25% of Oregon's newborns were receiving hearing screening. Only six of 60 hospitals and birthing centers voluntarily provided universal newborn hearing screening. Two additional hospitals screened only high-risk neonates. These programs were no more than three years old.

During 1999, only 15 infants under six months of age with PCHL were enrolled in Early Intervention facilities in Oregon. Based on the estimated frequency of PCHL, a well-running system should have identified and enrolled

approximately 100 infants. This is an indication of the extent of the need for an early hearing [loss] detection and intervention (EHDI) program, including universal newborn hearing screening, in Oregon.

Overview of Past Efforts to Identify Infants with Hearing Loss

From 1989 through 1992, the Oregon Health Division's Center for Child and Family Health (CCFH; subsequently renamed the Department of Human Services, Office of Family Health) received a grant from the U. S. Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB), through Utah State University, to create a Newborn Hearing Registry for high risk babies. The following risk factors associated with hearing loss were identified from birth certificates: low birth weight, gestational age less than 36 weeks, family history of hearing loss, transfer to intensive care unit, low APGAR scores, assisted ventilation over 30 minutes, and newborn conditions such as infection, birth injury, and congenital anomalies.

In 1990, the Child Development and Rehabilitation Center of the Oregon Health & Sciences University and the Center for Child and Family Health (CCFH) implemented the Oregon Newborn Hearing Registry. From 1990 until 1996, the CCFH mailed approximately 300 letters each month to parents of newborns with the above-mentioned risk factors indicated on their birth certificates. Each letter told the parent that the child might be at risk for hearing loss and suggested that they have the infant's hearing screened.

Unfortunately, the number of parents of at-risk children who ultimately received follow-up hearing screening declined each year; out of more than 4,000 letters in one year, less than 100 parents sought hearing screening. The Registry appeared to identify, at most, two infants each year who would not have been identified through any other source. In 1996, after engaging community audiologists in a needs assessment process, it was decided to cease the Newborn Hearing Registry and to pursue legislation to mandate universal screening

(Oregon Advisory Committee on the Universal Detection of Newborns with Hearing Loss, 1998).

Studies have shown that only half of all newborns with PCHL have even a single identifiable risk factor (Elssmann, Matkin, & Sabo, 1987; Feinmesser, Tell, & Levi, 1982; Mauk, White, Mortensen, & Behrens, 1991; Mehl et. al., 1998; Pappas & Schaibly, 1984; Watkin et. al., 1991). Ideal follow-up would still miss half of all affected newborns; ascertainment, in practice, is much lower (Mahoney & Eichwald, 1987).

Legislative Efforts

During the 1997 Oregon Legislative Session, a bill calling for a study to look at the value of universal newborn hearing screening, technological resources currently available, and options for implementing a statewide screening program passed both the House and the Senate. The Governor, because of unrelated last minute amendments, eventually vetoed the bill. The Health Division was instructed by legislators supportive of the study bill to look at the issue during the interim and the Division agreed.

In early 1998, the Health Division convened the Oregon Advisory Committee on Universal Detection of Newborns with Hearing Loss to review the issue. This was a broad-based panel including physicians, audiologists, hospital representatives, educators, advocates and consumers. In October 1998, the Advisory Committee issued a report recommending that Oregon should move towards the National Institute of Health and American Academy of Pediatrics recommendations to implement a program to detect hearing loss in ALL newborn babies. The report recommended that the program be phased in over six years, expanding to include all birthing hospitals and birthing centers. It was also recommended that the Health Division monitor the system to ensure that newborns were screened, to coordinate the follow-up of children with abnormal screening results, and to collect data to evaluate the program. The Advisory Committee played an active and important role in lobbying for passage of the legislation.

During the 1999 legislative session, the Oregon Legislature adopted House Bill 3246, mandating newborn hearing screening in hospitals with more than 200 live births per year. This was to be implemented July 1, 2000. The 39 mandated hospitals with more than 200 live births in 1998 delivered 91% of all Oregon newborns.

The elements of this inaugural legislation were the result of a political compromise. Mid- to large-size hospitals were required to screen; smaller hospitals and birthing centers were exempted. Hospitals were required to report annual aggregate numbers of newborns screened and newborns "with abnormal results." However, there was no requirement for individual-level reporting of screening, diagnostic testing and Early Intervention enrollment, which would allow the Health Division to monitor the process and evaluate the effectiveness of the program. No funds were provided for the Health Division to administer the program or for the hospitals to provide the services. Insurance carriers were not mandated to cover the service; Oregon's Medicaid program did not.

Preparation for Implementation

The Center for Child and Family Health was charged with providing technical information to screening hospitals, non-screening hospitals and birthing centers. Parents were to be informed by the smaller hospitals (not providing screening) about the need for screening and locations of outpatient screening facilities. The law did not set standards for follow-up diagnostic testing although it did require the CCFH to furnish hospitals a referral list of audiologic diagnostic facilities to be given to parents whose infants failed the screening. It did not prohibit hospitals from making referrals to other facilities. Audiologic diagnostic facilities were to provide parents with a CCFH-generated list of early intervention providers.

One of the first actions taken by the CCFH, in October 1999, was to mail out a survey to all Oregon-licensed audiologists hoping to identify those who were capable of performing diagnostic testing on infants. About one third of the respondents indicated they had the ability,

but very few had actually tested any infants in the preceding 12 months. Many respondents were interested in being trained to do the testing. The end result however was that CCFH did not feel that it could identify those with sufficient experience for testing infants, based on the survey alone.

The CCFH reconvened an expanded Advisory Committee. Bringing together staff members of the CCFH, advocates and parents, health professionals and hospital and health care organization representatives, this advisory committee proved invaluable. The Advisory Committee began meeting in November 1999. It was invaluable in assisting CCFH in designing and implementing a statewide program and achieving consensus among all the stakeholders.

The Advisory Committee established several subcommittees, including a technical subcommittee of audiologists. One of the audiologists had had experience establishing and running a hospital-based universal screening program in a large Oregon hospital. One critical issue the subcommittee took on was defining "a screening test," a term the law left undefined. In the end, at the subcommittee's urging, the Advisory Committee agreed that "a screening test" would require a "second attempt" if the baby did not pass the "first attempt." CCFH eventually incorporated a two-stage screening process into the administrative rules. The choice of screening technology, otoacoustic emissions (OAE) or automated auditory brainstem response (AABR), is not specified for either the first or second attempt, (e.g., OAE followed by AABR), and a variety of combinations are seen in the different hospitals.

This subcommittee also addressed the issue of the criteria for placing audiologists on the official diagnostic facilities referral list. The subcommittee considered and rejected various certification or competency-testing options as unworkable. It eventually decided to develop a very detailed and specific diagnostic protocol (DHS Office of Family Health, 2000a). The CCFH then surveyed audiologists and asked them if they had: 1) the competence to carry out our protocol, 2) the equipment to carry out our

protocol, and 3) the desire to be placed on the diagnostic facilities list. This survey was mailed out in March 2000 and from this CCFH identified 12 facilities able to provide the diagnostic testing, including three located in border areas of Washington and Idaho. Only those who answered affirmatively to all three questions were placed on the list. CCFH relied on their sense of professionalism and assumed that their answers were accurate.

Finally, the subcommittee took up the issue of audiologists vs. neurologists as diagnostic testers. Audiologists were concerned that neurologists had generally performed click-stimulus high-decibel ABR screening to assess the intactness of the neural pathways (providing no threshold information) and would object to the diagnostic protocol. The subcommittee brought an electrophysiologic neurologist onto the committee. In the end, this proved to be a non-issue and our protocol was generally accepted as the standard of care. Neurologists were surveyed along with audiologists but no neurologist sought to be placed on the referral list.

The legislation was somewhat confusing when defining an early intervention (EI) institution and the representatives of the private providers on our Advisory Committee were concerned that they would be excluded from our EI referral list. Again, the Advisory Committee established a subcommittee to create criteria for placement on this list and acceptable language was devised. One of the most important – and most difficult – tasks of the Advisory Committee was coming up with administrative rules. The most controversial issue was defining the extent of hospital responsibility for the screening if a baby left the hospital before receiving the test. The legislation seemed to place the responsibility for screening squarely on the hospitals and indicated it should be completed within one month and preferably before discharge. In the end, this was the position expressed in the administrative rules. The CCFH avoided placing specific requirements for contacting parents whose babies left without the testing, as CCFH believed that this would not protect the hospitals from liability but might increase the Oregon

Health Division's liability if a child with a hearing loss was missed. Hospitals were left to develop their own protocols for attempting to fulfill their responsibilities under the law.

Meanwhile, the Health Division identified, at each hospital, contact people who would be responsible for implementing their screening program and disseminated to them the Maternal and Child Health Bureau booklet on how to establish a screening program, along with lists of available equipment and staff training guidelines.

In an effort to get the word out, the Oregon Health Division (subsequently renamed Department of Human Services, Health Services) distributed a press release in April 2000. The CCFH program coordinator also gave a presentation at a symposium targeting professionals, primarily audiologists, organized by Oregon Health & Sciences University. The May 2000 issue of the CD Summary, a Health Division newsletter sent to all health care providers in the state, as well as the media, was devoted to newborn hearing screening. A web page was created, with resources for parents and providers (DHS Office of Family Health, 2000b). Finally CCFH participated in a press conference at a Portland hospital that included demonstrations of screening. All of these efforts generated print, radio and TV interviews and exposure.

CCFH, with the help of the Advisory Committee, developed an informational flyer, in English and Spanish, on the importance of screening, and eventually distributed this, along with lists of audiologic facilities able to perform screening for dissemination, to families of infants born at non-screening hospitals and freestanding birthing centers. One page of the CCFH's new "Newborn Handbook" was devoted to hearing screening; this handbook is given to all new parents before they leave the hospital. Later, in August 2000, the Advisory Committee developed a resource packet for parents of infants newly diagnosed with hearing loss and CCFH distributed this to all diagnostic facilities.

During the spring of 2000, several hospitals began implementing screening programs in advance of the deadline. Other hospitals were slowed by the rush to purchase equipment and resultant backlogs. The law went into effect on July 1, 2000.

The Good, the Bad and the Unfinished

Currently, 44 hospitals offer screening, including five smaller, non-mandated hospitals; nine non-mandated hospitals and four birthing centers do not. The screening hospitals deliver more than 96% of Oregon’s babies. Non-screening hospitals and birthing centers account for 3% of Oregon births; 1% of Oregon’s babies are born at home.

Early intervention relies on a long-standing pre-established regional system of state-funded EI covering the entire state, supplemented by the two private providers. And the program has been implemented with the apparent consensus of all major involved parties.

Many hospitals set up programs without the involvement of audiologists. While not absolutely necessary, the participation of audiologists certainly makes things run more smoothly. There are only a limited number of audiologists able to perform diagnostic testing and the Department of Human Services, Office

of Family Health (DHS OFH, formerly called the Health Division’s Center for Child and Family Health) has limited resources to train others; in addition, frequency-specific ABR equipment is quite expensive.

Impact of the New Law on Newborn Hearing Screening Rates

Oregon Pregnancy Risk Assessment Monitoring System (PRAMS) is a stratified random survey of postpartum women (DHS Office of Family Health, 2001). The survey is sent when the baby is 2-3 months old. Oregon PRAMS began in 1998.

Starting in May 2000, a question was inserted into Oregon PRAMS asking whether the baby got a hearing screening test before newborn discharge. (The law had been passed in August 1999 with an implementation date of July 1, 2000; some hospitals had been screening even prior to the passage and some others began their programs early, in anticipation of the implementation date.) The proportion screened increased dramatically once the new law took effect. By August-September nearly 95% of newborns were being screened. Table 1 displays the data from Oregon PRAMS; responses were excluded if the mother did not know whether or not her newborn had been screened (Rosenberg, Dale, & Sandoval, 2002).

Table 1
Oregon PRAMS: Mothers Reporting That Their Newborn Received Hearing Screening, February-November 2000

Month of Birth	Screened	Not Screened	Total	% Screened
February 2000	27	14	41	69.9
March 2000	63	46	109	57.8
April 2000	58	32	90	64.4
May 2000	56	26	82	68.3
June 2000	80	20	100	80.0
July 2000	106	7	113	93.8
August 2000	120	7	127	94.5
September 2000	110	6	116	94.8

Recent Developments

An expanded mandate was passed by the Oregon legislature in 2003. The new law allows DHS to establish a registry of all newborns, as well as a follow-up and tracking system. It requires hospitals, birthing centers, diagnostic facilities and early intervention (EI) centers to report individual-level screening and diagnostic testing results, as well as early intervention referrals and enrollment, to OFH. The requirement for individual-level reporting went into effect January 2004. Although this law continued to exempt hospitals and birthing centers with less than 200 births per year, many small facilities have voluntarily complied with its terms.

Supported by the expanded legislative authority, Oregon has developed the Newborn Hearing Registry and Tracking system. The Oregon Office of Vital Statistics added a field for the newborn metabolic screening (NBMS) identification number to the electronic birth certificate allowing newborn hearing screening (NHS) results to use the same number. This allows the NHS results to be linked to the birth certificate so the state health department can identify all newborns who have not received a newborn hearing screening test.

The Newborn Hearing Registry and Tracking System allows the EHDI program to identify infants who have not been screened or who have failed to pass the screening tests. If a baby is born in a mandated hospital and is six weeks old and the OFH has no screening results, then staff send letters to parents and providers recommending that the baby get screened (with a list of screening facilities). If baby has been screened but has failed the screening and the OFH has not received the results of diagnostic audiologic testing, staff send a letter to the parents and providers recommending further testing (and providing a list of testing facilities). If the OFH has a diagnosis of hearing loss but have not received a contact report from an EI facility, staff contact parents, providers and local public health to facilitate getting the baby to EI for needed services.

Future Challenges

Now that the key elements of an EHDI system are in place, it is our objective to see that the Joint Committee on Infant Hearing goals are realized: screening by one month of age, identification by three months of age and intervention by six months of age (Joint Committee on Infant Hearing, 1995). To achieve this requires the coordination and cooperation of all participants in the process – the Office of Family Health, hospitals, primary care providers, audiologists, educators...and parents.

Parents must be given sufficient educationally and culturally appropriate information in the nursery so that they can understand the importance of and limitations of the screening their baby has received, and be motivated to seek diagnostic testing if needed, without unduly alarming them. Health educators must walk a fine line between under- and over-whelming new parents, who are already bombarded by health messages on a myriad of health topics.

One of the greatest problems of any EHDI system is ensuring that infants successfully move from one component of the system to the next, from hospital to diagnostic center and from diagnostic center to early intervention program. Many programs report that follow-up has been poor and it is estimated that about half of all infants failing screening tests do not receive diagnostic testing (National Center for Hearing Assessment and Management, 2004). Oregon's experience, based on estimates from aggregate-level reporting, has been similar.

Because these separate components of the EHDI system are generally organizationally distinct, a great responsibility falls on the parents for arranging for post-hospital evaluations. Many barriers, including educational, financial, cultural and linguistic, are likely to interfere. It is our responsibility to utilize the information in the EHDI registry, linked to the wealth of demographic and socioeconomic information in the birth certificate registry, to identify population-level barriers to successful navigation of the EHDI system, and then to

target culturally-competent health education at those groups at risk for loss to follow-up.

Health educators and health promoters will play a key role in this effort.

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Author Information

Martin B. Lahr, MD, MPH *†
Oregon Department of Human Services
Disability Determination Services
3150 Lancaster Dr. NE
Salem, OR 97305-1350
Ph.: 503-947-5117
Fax.: 503-373-7202
E-mail: martin.b.lahr@state.or.us

Kenneth D. Rosenberg, MD, MPH
Maternal & Child Health Epidemiologist
Oregon Department of Human Services
Office of Family Health
800 NE Oregon Street, Suite 850
Portland, OR 97232
Ph.: 503-731-4507
Fax.: 503-731-4091
E-mail: ken.d.rosenberg@state.or.us

* Corresponding author

† Former EHDI Program Coordinator, 1999-2000, Center for Child and Family Health