DOCUMENT RESUME

ED 357 547 EC 302 090

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TITLE Early Identification of Hearing Impaired Children: Expanding and Refining Best Practices. Final Report.
INSTITUTION Utah State Univ., Logan. Dept. of Psychology.
PUB DATE 25 Feb 93
NOTE 220p.; A portion of the document contains small, light print.
PUB TYPE Reports - Descriptive (141) -- Reference Materials - Bibliographies (131)

EDRS PRICE MF01/PC09 Plus Postage.
DESCRIPTORS *Acoustics; At Risk Persons; Auditory Evaluation; *Auditory Tests; *Diagnostic Tests; Evaluation Methods; *Handicap Identification; *Hearing Impairments; Incidence; Infants; National Programs; Neonates; Program Development; Program Effectiveness; *Screening Tests
IDENTIFIERS *Early Identification; High Risk Registry; Otoacoustic Emissions

ABSTRACT

The goal of this project was to increase by 50 percent the number of children with significant hearing impairment identified by 12 months of age. Attainment of this goal was attempted through activities in three major areas: (1) replication and documentation of the benefits of a birth certificate-based screening system; (2) investigation of the feasibility of using transient evoked otoacoustic emissions (TEOAE) to identify hearing loss in infants; and (3) refinement of procedures for operating a birth certificate-based screening system. Project research confirmed that properly implemented birth certificate-based high-risk registers are a feasible and effective means of identifying children with sensorineural hearing impairment at an early age, but the use of a high-risk registry is not enough, as almost 40 percent of hearing-impaired children do not exhibit any of the risk factors. Project data also indicate that it is feasible to use TEOAE as a hearing-screening tool for every live birth, that TEOAE accurately identifies sensorineural hearing loss, and that it indicates those infants most at risk for conductive hearing losses. Appendices comprise over half of the document and contain: (1) project products such as checklists, promotional information, survey forms, a screening protocol, and information for parents; (2) professional papers, including "The Effectiveness of Screening Programs Based on High-Risk Characteristics in Early Identification of Hearing Impairment," "Neonatal Hearing Screening Using Evoked Otoacoustic Emissions: The Rhode Island Hearing Assessment Project," and "Identification of Children with Hearing Impairments: A Baseline Survey"; and (3) a list of over 500 references on early identification of hearing impairment in children. (JDD)

Mauk, G. W.

Final Report

for

Early Identification of Hearing Impaired Children: Expanding and Refining Best Practices

Project Number: MCJ-495037-01-0

June 1, 1989 through May 31, 1992

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February 25, 1993

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I. PURPOSE OF PROJECT AND RELATIONSHIP TO SSA TITLE V MATERNAL AND CHILD HEALTH PROGRAMS. The challenge of early identification, diagnosis, and habilitation of hearing loss in children is critical, whether the hearing loss is unilateral or bilateral; sensorineural, mixed or conductive; or mild, moderate, severe, or profound (Chase, 1992). Despite the recognized value of early identification of hearing loss, the U.S. has been dilatory in its efforts to develop hearing screening programs, especially for neonates. Currently, only between three and five percent of all newborns in this country are screened for hearing impairment (Bess & Hall, 1992; Colorado to Screen, 1992) and, tragically, the average age at which children with significant hearing impairments are identified in the United States is reported to be 2-1/2 years (Academy of Otolaryngology-Head and Neck Surgery, 1990; Commission on Education of the Deaf, 1988). This relatively late age at which children in the United States are identified limits their access to early intervention services and increases the probability of adverse educational and psychosocial consequences as they mature.

Public Law 101-239 (the Omnibus Budget Reconciliation Act of 1989) amended Title V of the Social Security Act to extend the authority and responsibility of the Maternal and Child Health Bureau to more fully address the needs of children with special health care needs. Section 501(a)(1)(D) states that one of the purposes of the law is

"To provide and to promote family-centered, community-based, coordinated care (including care coordination services) for children with special health care needs and to facilitate the development of community-based systems of services for such children and their families."

Although many children with special health care needs have suffered from the unavailability of appropriate care as defined by this law, children with significant hearing losses have suffered as much as any.

Because the ability to hear during the first three years of life is critical for the acquisition of spoken language, failure to identify hearing loss and provide intervention (amplification, speech therapy, and/or sign language instruction) within the first year of life has a needless negative effect on language development beyond the effect of the hearing loss itself (Downs, 1986; Ross, 1990). The importance of earlier intervention is underscored by the fact that children with hearing losses who receive intervention before two and one-half years of age have significantly better communicative skills than children who receive similar intervention at later ages (Clark, 1979). Such improved communication skills are basic to future psychosocial, educational, and vocational development (Bebout, 1989; Garrity & Mengle, 1983; Madell, 1988; Sacks, 1989; Schum, 1987).

There is broad agreement by professionals in the field of special education that the early identification of hearing loss has substantial benefits. If children can be identified early, fitted with appropriate amplification, and provided with appropriate community-based, family-centered, coordinated early intervention services, substantial reduction in later special education costs for these children will be realized. The difference in later special education costs for each child as a result of early identification and intervention can easily be as much as $20,000 per child for children with severe to profound sensorineural hearing losses. Just as important is that fact

that children who heretofore have not been identified until a later age or who have remained unidentified and have suffered the disabling effects of an undetected hearing loss will be identified at an early age and provided with habilitative services.

Although there is widespread agreement that early identification of hearing loss is extremely important, little progress has been made during the last 40 years in reducing the average age at which identification of hearing impairment occurs (Jerger, 1990). Fortunately, however, it now appears as if the issue of early identification of hearing loss is being taken more seriously. For example:

- In 1978, there were only 3 states with legislative mandates for newborn hearing screening; now there are 16 and the number is growing rapidly (see Johnson et al., 1993);
- For the first time, the federal government has set a specific goal to lower the average age at which hearing impairment is identified instead of just talking about its importance (see U.S. Department of Health and Human Services, 1990, p. 460); and
- A new National Institute on Deafness and Other Communicative Disorders (NIDCD, 1989) was recently established and has outlined a national strategic research plan that identifies "improved methods for early screening and diagnosis of hearing loss in infants and young children" (p. 63) as one of its primary goals.

Given the widespread and long-standing recognition that hearing loss has serious negative consequences, it is not surprising that the federal government has

become involved in efforts to address the deleterious efforts of hearing loss in young children. Over the last 40 years, numerous conferences, advisory committees, and research projects have been funded by various federal agencies. A brief summary of some of the more significant efforts provides a useful context for understanding and shaping current attempts to reduce the average age at which hearing loss is identified.

The Babbidge Report

Federal governmental interest in initiatives related to early identification of hearing loss dates back to at least 1965, when a report to the Secretary of Health, Education, and Welfare recommended the development and nationwide implementation of ". . . universally applied procedures for early identification and evaluation of hearing impairment" (Babbidge, 1965, p. C-10). This same report stated:

> We must move promptly and vigorously on several fronts . . . [to] expand and improve our programs of early attention to the deaf child . . . . the infant with a hearing defect or a potential hearing defect should have a better chance of being identified in the early months of life. (p. xvi)

National Conference on Education of the Deaf

Two years later, the Report of the National Conference on Education of the Deaf (often referred to as the Colorado Springs Conference; U.S. Department of Health, Education, and Welfare, 1967) made the following recommendations:

- A high-risk register[1] to facilitate identification of young children with hearing problems should be adopted immediately; (p. 66)
- The public information media should be used to make hearing loss as common a concern as cancer and heart disease; (p. 69) and
- Testing of newborn infants and children six to 12 months old should also be investigated, with particular attention to the question of cost-effectiveness. (p. 70)

Commission on Education of the Deaf

Despite these bold edicts, progress regarding early identification of hearing impairment has been painfully slow. Currently, of the approximately 4 million live births in the United States each year, 95 to 97 percent are not tested for hearing disability (Bess & Hall, 1992; Colorado to Screen, 1992). According to a report released in 1988 by the Commission on Education of the Deaf to the President and Congress of the United States, " . . . more than 20 years [after the Babbidge Report], the average age of identification for profoundly deaf children in the United States is reported as 2 and 1/2 years (p. 3). The Commission's report went on to recommend that "The Department of Education, in collaboration with the Department of Health and Human Services, should issue federal guidelines to assist states in implementing improved screening procedures for each live birth" (p. 6).

Advisory Group on Early Identification of Children with Hearing Impairments

In response to the Commission's report, the Office of the Assistant Secretary

[1]The high-risk register was originally proposed as a part of the Toronto Conference held on October 8th and 9th of 1964 (see Davis, 1965).

of Special Education and Rehabilitative Services of the U.S. Department of Education in collaboration with the Office of Maternal and Child Health of the U.S. Department of Health and Human Services (HHS) convened an advisory group of national experts in April, 1988 to advise the federal government about ". . . the feasibility of developing guidelines, the content to be included in the guidelines, and the process that should be used in implementing such guidelines" (Advisory Group on the Early Identification of Children with Hearing Impairments, 1988, p. 1). The advisory group concluded that the federal government could promote early identification of hearing-impaired children most effectively by funding demonstration projects to expand and to document systematically the cost efficiency of the proven techniques already in existence but infrequently used.

Healthy People 2000

In 1988, C. Everett Koop, the then Surgeon General of the U.S., issued a challenge that by the Year 2000, 90% of all children with significant hearing loss should be identified by 12 months of age. Simultaneously, the Public Health Service initiated a campaign to make parents aware of behavioral indicators of childhood hearing loss. At about the same time, the U.S. Department of Health and Human Services (1990) was involved in a massive project "to focus existing knowledge, resources, and commitment to capitalize on our opportunities to prevent premature death and needless disease and disability" (p. i). The result was a report, Healthy People 2000: National Health Promotion and Disease Prevention Objectives, released in 1990, which committed the federal government to work toward the accomplishment

of a series of objective, specific, attainable goals designed to improve the health of our country's citizens by the Year 2000. It is noteworthy that a goal was included to "reduce the average age at which children with significant hearing impairment are identified to no more than 12 months" by the year 2000 (HHS, 1990, p. 460). With this goal in mind, this SPRANS Project was funded out of MCH Set-Aside funds to increase by 50% the number of children with significant hearing impairment identified by 12 months of age.

II. GOALS AND OBJECTIVES

Although the importance of screening young children for hearing loss has been consistently proclaimed by the federal government over the last 40 years, it has only been recently that technology has evolved to the point where widespread newborn hearing screening activities are being proposed and implemented. In considering which screening approach is most likely to achieve the goal of reducing the average age of identification to 12 months, the criteria suggested by Redell and Calvert (1969) more than 20 years ago are still valid. The procedure should be valid in identifying a high proportion of those with significant hearing impairment, efficient in screening out those with no significant hearing impairment, inexpensive, and applicable to a wide variety of prestimulation conditions (e.g., infant state, environmental noise).

Attempts to screen the auditory function of neonates and infants date back almost 50 years (Davis, 1965; Downs & Sterritt, 1967; Ewing & Ewing, 1947; Froding, 1960; M. Reed, personal communication, July 20, 1992; Simmons, 1978; Wedenberg, 1956), and during this time debate has raged over the most appropriate,

effective, and cost-efficient neonatal/infant hearing screening approaches and techniques. As stated above, the goal of this SPRANS project was to increase by 50% the number of children with significant hearing impairment identified by 12 months of age. Attainment of this goal was attempted through activities in three major areas:

1. Replication and documentation of the benefits of a birth certificate-based screening system. The procedures used during the past twelve years in Utah were be replicated and systematically evaluated and documented in Oregon;

2. Investigation of the feasibility of using transient evoked otoacoustic emissions (TEOAE) to identify hearing loss in infants. Using TEOAE as an initial screening procedure followed by evaluating children who fail the TEOAE with portable ABR equipment, a program to evaluate the feasibility and cost efficiency of TEOAE was implemented in a major hospital in Rhode Island; and

3. Refinement of procedures for operating a birth certificate-based screening system. Using several years of data from a birth certificate-based screening program in Utah, retrospective analyses were conducted to determine how the program could be refined and improved.

III. METHODOLOGY

OREGON: Replication and documentation of the benefits of a birth certificate-based screening system. In June, 1989 the Project initiated plans to replicate the birth certificate-based high-risk registry system for early identification of hearing loss in the state of Oregon. Prior to this time, Oregon did not have a

systematic procedure for identifying infants at-risk for hearing loss.

Oregon first established an Advisory Council to establish procedures for implementing the Utah system of birth certificate-based screening. This system served as a forerunner to Oregon's broader high-risk screening and tracking system for all children with handicaps with the intent of using local health departments as the referral points for each county. Each health department now receives a monthly list of parents of infants at high-risk of hearing impairment. A computerized mailing system was designed and established at the Oregon Health Division (OHD) for mailing of the high-risk notices to parents (the results of these mailings are presented in the Results/Outcomes section of this Narrative). A plan for referral contact for parents was presented to Oregon Department of Education and regional staff and to County Public Health Nurses (CPHNs). It was decided that CPHNs would serve as primary referral contacts.

A retrospective survey of 46, six-year-old children with impaired hearing was conducted by the Project during April-May, 1990. The results of this baseline survey and the results are presented in the Results/Outcomes section of this Narrative.

RHODE ISLAND: Investigation of the feasibility of using TEOAE to identify hearing loss in infants. The original Project proposal called for implementing a birth certificate-based screening program in two states, Oregon and Iowa. Unfortunately, Department of Health staff in Iowa were unable to modify their birth certificate to include the necessary information. At the same time, the technology for transient-evoked otoacoustic emissions (TEOAE) and portable auditory brainstem response

(ABR) equipment advanced to the point that these devices became commercially available.

During the second year of the Project, we had planned to investigate alternative methods for identifying children who did not exhibit the high-risk criteria used in the birth certificate-based program. By using OAE and ABR with all live births, we postulated that a screening program might be developed that would even be more cost-efficient than the birth certificate-based screening program.

The feasibility of using TEOAE as an initial screening procedure with all live births, followed by evaluating children who fail the TEOAE with portable ABR equipment, was evaluated at a major hospital in Rhode Island. The plan for June 1, 1991 to October 31, 1991 was to continue screening using the current protocol. During the 1991-1992 year, the focus of the Project was be to collect additional data to refine the screening protocol and to determine the cost efficiency of the TEOAE procedure compared to alternative procedures.

The plan for November 1, 1991 to December 31, 1991 called for screening every live birth using OAE and collecting cost efficiency data. The plan for January 1, 1992 to May 30, 1992 included (a) continuation of re-screening, (b) cleaning and refining of data, (c) detailed analysis of the results, (d) conducting cost analyses, (e) preparation and dissemination of materials, (f) exploration of feasibility testing in pediatricians' offices, and (g) initiation of arrangements for implementation of state-wide neonatal screening.

UTAH: Refinement of procedures for operating a birth certificate-based

screening system. The use of the high-risk registers using the variables recommended by the Joint Committee on Infant Hearing (1982) is one method of identifying sensorineural hearing loss at an early age. One of the longest used and apparently successful methods of collecting information about the presence of these risk factors is to incorporate the relevant information into the legally-required birth certificate, as has been done in Utah since 1978 (Mahoney & Eichwald, 1986, 1987). This system uses a birth certificate protocol to gather information about the following seven high-risk factors identified by the Joint Committee on Infant Hearing (1982):

1. A family history of childhood hearing impairment.

2. Congenital perinatal infection (e.g., cytomegalovirus, rubella, herpes, toxoplasmosis, syphilis).

3. Anatomical malformations involving the head or neck (e.g., dysmorphic appearance including syndromal and nonsyndromal abnormalities, overt or submucous cleft palate, morphologic abnormalities
of the pinna).

4. Birth weight less than 1500 grams.

5. Hyperbilirubinemia at level exceeding indications for exchange transfusion.

6. Bacterial meningitis, especially *Haemophilus influenzae.*

7. Severe asphyxia (often measured with Apgar scores between 0 and 3 or infants who fail to institute spontaneous respiration by ten minutes and those with hypotonia persisting to two hours of age).

The success of any screening system for hearing impairment depends on

the degree to which the following three conditions are met:

1) Children with sensorineural hearing loss exhibit the risk factors;

2) Children with risk factors can be located for additional diagnostic testing; and

3) Appropriate follow-up services can be provided following initial suspicion and/or confirmation of a hearing loss.

Unfortunately, even though the risk factors recommended by the Joint Committee on Infant Hearing have been widely advocated for over 15 years, very little empirical evidence is available about how well the three preceding conditions are met.

One of the problems with determining the efficiency of screening systems designed to identify sensorineural hearing loss is that the presence of the hearing loss for some children is often not confirmed until three to five years later. Thus, it is difficult to know how successful the system is unless the system has been in place for an extended period of time. Because the system used in Utah has been in place since 1978 and records have been maintained, there was a unique opportunity to analyze how successful the system has been in identifying sensorineural hearing loss. In 1989-1990, a retrospective survey of parents of six- to nine-year-old children was undertaken by the Project to discover the patterns of identification of six- to nine-year-old children with educationally-significant, sensorineural hearing losses who were attending programs operated by the Utah School for the Deaf and who were born in Utah during the time that the birth

certificate-based registry was in full operation. The purpose of this study was to use archival information from the birth certificate-based screening program together with information about the child's hearing loss and parents' responses to a survey to determine how effective such a screening program is and what factors are associated with earlier or later identification and habilitation of sensorineural hearing loss. In addition, during April, 1991, a survey of non-respondents to the birth certificate-based high risk registry program was conducted by Utah Bureau of Communicative Disorders with the assistance of the Project (Mahoney, Eichwald, & Fronberg, 1992). The results of these retrospective surveys are presented in the Results/Outcomes section of this Narrative.

IV. EVALUATION

Because the goal of this project was to identify greater numbers of children with hearing losses at younger ages, the success of the project could be measured in terms of how many additional children with impaired hearing are identified and the ages at which they are identified. These data can be compared to current information about the number of children identified and the ages at which they are identified yearly in each participating state.

Another source of evaluative data was the degree to which state agency administrators are willing to assume the costs of continuing the screening programs after the federal funding for the project has been completed. Advisory Committees were formed in Oregon and Rhode Island to review project progress and results and provide feedback and guidance which were incorporated

appropriately into project activities. Regular discussions with state agency staffs in both Oregon and Rhode Island continued to indicate a high probability that these programs will be continued with state funding after the federal project period.

In addition, outside consultants were used: (a) to provide feedback to the key staff about how well the project was achieving its goals; and (b) suggest procedural refinements, necessary adjustments, and future directions.

V. RESULTS/OUTCOMES

Oregon

High-risk mailings. The first high-risk mailing to parents occurred on February 27, 1990 for children born during August, 1989. From August, 1989 through April, 1991, and reported in November, 1991, there were a total of 73,528 births in the state of Oregon. A total of 7,050 high-risk notices were mailed to parents: 3,369 (48%) were not returned; 715 (10%) were undeliverable; and 2,966 (42%) were returned. The last mailing for which complete data were received under this Project, a total of 3,754 high-risk notices had been mailed. Forty percent (1,494) were returned. Of the 2,966 who returned a response card, 1,374 (46%) requested assistance from the Oregon Health Division (OHD), 569 (19%) reported that they would make their own appointment to have their child's hearing evaluated, 345 (12%) requested no testing, 397 (13%) reported that the high-risk data on their child's birth certificate was incorrect, and 281 (9%) reported that they had already had their child's hearing tested. Of the 281 who reported having their child's hearing tested, 263% (94%) reported that their

children passed and 18 (6%) did not pass. Of the 1,374 parents requesting assistance from the OHD, 187 (14%) were unable to be contacted, 165 (12%) changed their minds, 19 (1%) broke their appointments, 611 (45%) were "in process" (e.g., awaiting an audiological appointment, initial screening was inconclusive, test results not reported to OHD), and 392 (29%) had hearing tests completed. Of the 392 who had hearing tests, 369 (94%) passed, 14 (4%) required retesting, and 9 (2%) failed.

Early identification training packets were produced and training sessions on procedures for assisting parents with early identification of hearing loss were conducted with regional nursing supervisors. A videotape emphasizing the importance of early identification of hearing loss was developed by the Project and disseminated widely.

Survey of audiologists. During the Fall of 1989, the Project conducted a survey of 120 licensed audiologists in Oregon to ascertain their interest in participating in screening of infants suspected of having hearing impairment. Using criteria developed by the Advisory Council, 33 audiologists were selected to participate; currently, 40 audiologists are in the system. A "Directory of Audiological Services for Infants" was produced and distributed to CPHNs.

Retrospective survey. A retrospective survey of identification of patterns of hearing impairment in 46, six-year-old children was conducted to establish a baseline for average ages of suspicion, testing, confirmation, amplification, and services (Moore, Josephson, & Mauk, 1991). This retrospective study was based

on the procedures and protocol developed in Utah (see protocol and results of the Utah retrospective survey explained in the Utah Results/Outcomes section of this Narrative).

The mean age of parental suspicion of a hearing loss was 22.2 months. The mean age for the child's first hearing test was 27 months (a 4.8 month delay), while the mean age at confirmation of a hearing loss was 30.6 months (a 3.5 month delay from first test to confirmation). The mean age at first habilitation (e.g., parent-infant program, speech-language services) was 36 months (a 5.5 month delay from confirmation). Finally, the mean age at first amplification was 38.7 months (a 2.7 month delay from the initiation of services).

Thirty-three (72%) of the children manifested at least one of the seven risk factors identified by the Joint Committee on Infant Hearing (1982 criteria). One-third of the parents of these children reported a history of family childhood-onset hearing loss. All children (n = 33) with at least one risk factor for a hearing loss ("high-risk") were compared on hearing milestones with the 13 children with no risk factor for hearing loss ("not high-risk"). The mean age of confirmation of a hearing loss in the two groups was examined and found to be earlier in the high-risk group, but only by 3.5 months. Even with a risk factor present, the mean age of identification for this group was 27.3 months of age.

The results of this retrospective study confirm that children with hearing impairments in Oregon are identified at approximately the same age (30.6 months) as children nationally (30 months). It is hypothesized that this age of

identification can be lowered with birth certificate-based screening for risk factors for hearing loss. Studies similar to the present one will need to be conducted in Oregon in the future to determine the actual impact of Oregon's recently established screening program. Results obtained in the present study provide baseline data for these future efforts.

Monitoring and dissemination. The activities of the Project were monitored via monthly teleconferences which are held with key staff members in each of the participating sites. Activities during the preceding months were discussed and any obstacles which were encountered in achieving the goals of the Project were noted, resolutions were identified, and the activities to be accomplished before the next monthly teleconference were discussed. Written minutes of these teleconferences were distributed to key staff members and to the project officer. As a result of issues discussed during the teleconferences, the principal investigator or other staff made regular site visits to each of the participating sites.

Meetings were held on numerous occasions with OHD staff and other agencies to explain Project needs, develop financing mechanisms for evaluating the children identified from birth certificate data, and establish and staff a telephone service for concerned parents. Information on guidelines for language development was developed by the Project and are now provided to all mothers after the birth of a child. This information is contained in immunization packets provided at all hospitals.

Presentations about the Project were given to several professional groups and organizations and small-group presentations were delivered to groups of educators and students throughout the state . To date, twelve presentations to the staff of as many hospitals have been conducted; hospital presentations are on-going.

Child census. Because the goal of this SPRANS grant is to lower the average age at which hearing impaired children are identified in participating states, the success of the project can be measured in terms of how many additional hearing impaired children are identified by 12 months of age. A census of 23 infants, born in Oregon between August, 1989 and November, 1991 served as "hearing-impaired" in the six regional educational programs in Oregon as reported to the Oregon Newborn Hearing Registry, was conducted by Ms. Jean Josephson in February, 1992. The census revealed that the average age of diagnosis of these 23 infants was 7.3 months, much below the Project goal of 12 months.

Cost analysis. In May, 1992, a cost analysis of the Newborn Hearing Registry was conducted by Dr. William Moore of the Teaching Research Division at Western Oregon State College. The results, which are contained in Appendix A, revealed that such a Registry in a state similar to Oregon would cost approximately $79,000 per year.

State integration. During 1991-1992, the Project shifted focus from state level operations to local community awareness, county public health response,

audiological assessment, and service delivery to families of at-risk and/or hearing impaired infants. Work continued to improve the accuracy of birth certificate data reporting and to improve the rates and outcomes of county public health nurse (CPHN) contacts with parents.

Procedures which have been undertaken to ensure fiscal and administrative adoption of the Project at the end of the funding period by the appropriate state agency include (a) verbal and written agreements with the OHD which state that the Project will become part of the larger "Babies First!" infant screening and tracking program, (b) written procedures within the OHD, (c) design of a data reporting system and incorporation of this system into regular OHD procedures, and (d) inclusion of language develop guidelines for parents in OHD immunization packet.

Rhode Island

Explanation of otoacoustic emissions. Otoacoustic emissions (OAEs) are acoustic responses associated with the normal hearing process. OAEs are produced in the inner ear and can be measured with a low-noise microphone placed in the ear canal (Kemp, 1978). A major subclass of OAEs is termed "transient evoked otoacoustic emissions (TEOAEs)," because these responses are commonly elicited by the use of brief acoustic stimuli such as clicks (Kemp & Ryan, 1992; Probst, Lonsbury-Martin, & Martin, 1991). Substantial evidence now shows that TEOAEs are a property of the healthy, normal-functioning cochlea, generated by active, frequency-selective, nonlinear elements within the cochlear

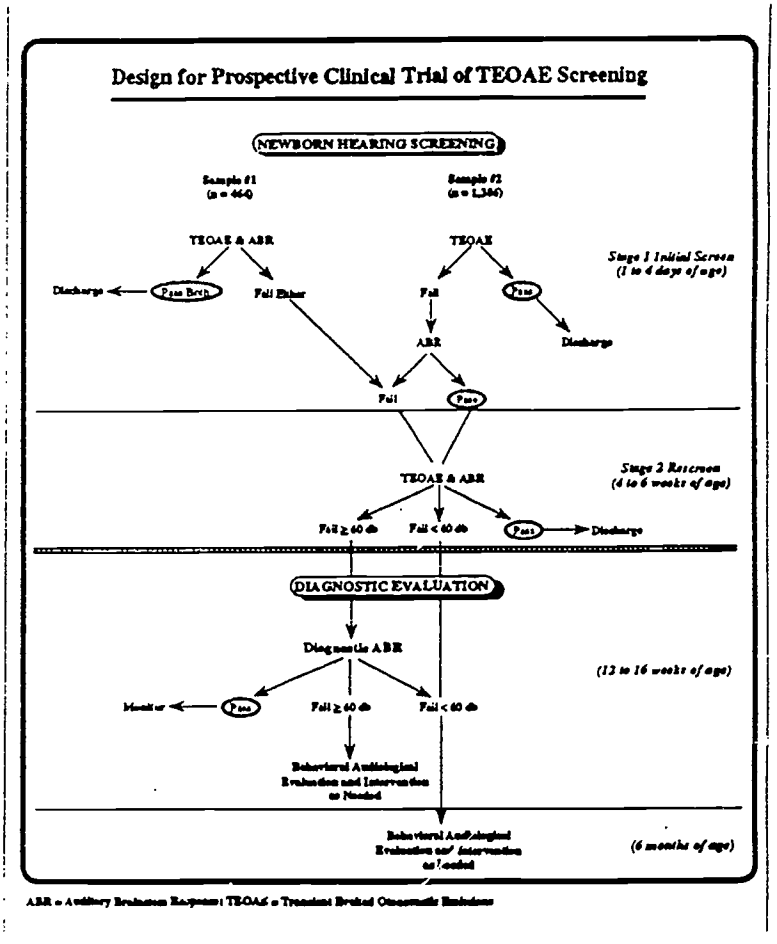
partition. These elements enhance the cochlear response to sound by a positive feedback mechanism, thus improving sensitivity and frequency selectivity.

The ease with which TEOAEs can be measured has led to the development of several commercial devices. One of these devices, the Otodynamic Analyzer (ILO88) (Kemp, 1988), has been used to identify impaired hearing in infants as demonstrated by an expanding body of research (Bonfils, Uziel, & Pujol, 1988a, 1988b; Elberling, Parbo, Johnsen, & Bagi, 1985; Johnsen, Bagi, & Elberling, 1983; Kemp, Bray, Alexander, & Brown, 1986; Lutman, Mason, Sheppard, & Gibbin, 1989; Uziel & Piron, 1991). Prior to the initiation of this project, TEOAE equipment had only been used with small numbers of infants in high-risk nurseries.

The Rhode Island Hearing Assessment Project (RIHAP). As described by Johnson, White, Maxon, and Vohr (1993), the Rhode Island Hearing Assessment Project (RIHAP) was initiated in February, 1990. By August 15, 1990, staff had been hired and trained, and the day-to-day procedures of operating a universal newborn hearing-screening program had been established. At this time, data collection was begun for the prospective clinical trial of TEOAE screening with infants cared for in the normal nurseries and the NICU at Women and Infants Hospital of Rhode Island. [Examples of the various forms, protocols, and procedures being used by the Project are included in Appendix A.] Data were collected for 1,850 infants born between August 15, 1990, and February 28, 1991,

whose parents provided informed consent.[2]

The design of the study, shown in Figure 1, included two different samples.



In the first sample, 464 infants were screened using both TEOAE and ABR, regardless of the results on either test. This was done to enable subsequent comparisons between TEOAE and ABR. In the second sample, 1,386 infants

[2]Data have subsequently been collected for an additional sample of 1,451 infants born between March 1, 1991 and December 22, 1992. Although not included in the results reported here, preliminary analyses of those data are consistent with the main conclusions presented herein.

were screened first with TEOAE, and then only those infants who did not pass the TEOAE were screened with ABR. Four to six weeks after leaving the hospital, infants in both samples who did not pass one or both of the initial screening tests (TEOAE or ABR) were retested with TEOAE and/or ABR in the second stage of the screening protocol.

Infants who did not pass the second stage of the screening process were referred for diagnostic ABR or behavioral audiological evaluation (Maxon, 1987), depending on the results of the second-stage screen. If the results of the second-stage screen with ABR indicated a hearing loss $\geq$ 60 dB, diagnostic ABR was done at 12 to 16 weeks of age, followed by a behavioral audiological evaluation and tympanometry. If the results of the second-stage ABR screen suggested a hearing loss < 60 dB, the behavioral audiological evaluation and tympanometry were not done until six months of age. The difference in timing of the diagnostic procedures was because infants with severe-to-profound hearing losses were in greater need of immediate intervention (i.e., fitting of amplification and enrollment in an early intervention program) than were infants with mild and moderate losses.

Procedures for TEOAE screening. A complete description of the screening procedures is provided elsewhere in this issue by Johnson et al. (1993). In brief, infants were brought to a testing room adjacent to the normal-care nursery and placed in a closed isolette. Trained technicians, supervised by an audiologist, used the IL088 Otodynamic Analyzer (Kemp, 1986) for TEOAE screening. Infants in

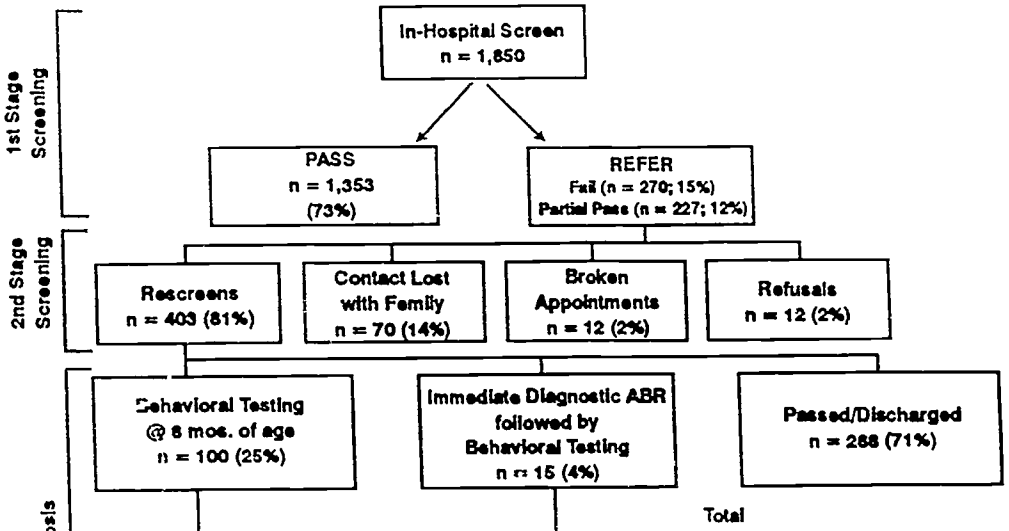
the normal-care nursery were usually screened 24 to 48 hours following birth, and infants from the NICU were screened during the week prior to discharge from the hospital. TEOAE screening required approximately 10 minutes per child.

Results of the initial TEOAE screening were scored by the supervising audiologist as a pass, fail, or partial pass. Pass was defined as an emission signal representing at least a 3 dB signal-to-noise ratio across the test frequency bands of 1 - 2 kHz, 2 - 3 kHz, and 3 - 4 kHz. A fail was indicated when there was no response in any frequency band. A partial pass was scored when an emission was present in one or two --- but not all three --- of the test frequency bands. Even though an infant with a partial pass did have an emission, the fact that the emission was not across the full range necessary for normal hearing led to a decision to "fail" that infant for that stage of the screening process and to refer the infant for further evaluation. The decision to refer infants with partial passes was different than previous applications of TEOAE newborn screening and was done to determine whether such emissions might be indicative of frequency-specific, progressive, or late onset hearing losses. More details regarding scoring and interpretation of TEOAE screening results are given elsewhere in this issue by Vohr et al. (1993).

As shown previously in Figure 1, infants who did not pass the first stage were referred for a second-stage screen at four to six weeks, using similar procedures, except that the infant was often held by the mother during testing. The rescreen at this second stage was done in the same hospital test area where

the initial screening was done. The rescreen with TEOAE required approximately 30 minutes per child because it was more difficult to establish appropriate conditions with the older children.

Results. Figure 2 summarizes the results of the newborn hearing screening for the period between August 15, 1990 and February 28, 1991. During this time,



mothers of 1,850 infants who were selected for screening agreed to participate (96% of the mothers who were approached agreed to participate). Infants screened were generally representative of all infants born at WIHRI as indicated by information collected regarding risk factors and other medical/demographic characteristics reported by Vohr, White, Maxon, Behrens, and Mauk (1993). Three hundred and four (16.4%) of the infants in the study were cared for in the NICU and 1,546 (83.6%) were cared for in the normal nursery. Of the 1,850

infants screened, 497 (26.9%) did not pass the initial stage of the two-stage screening process (270 of these exhibited no emission and 227 were scored as a partial pass). These infants were referred for the second stage of screening at four to six weeks of age. Of the 497 infants referred for second-stage screening, 403 (81%) were successfully rescreened. Of that group of 403 infants, 115 did not pass the second stage and were referred for a diagnostic evaluation (this represents 23.1% of the referred group, or 6.2% of the total group). A complete diagnostic evaluation, including a behavioral audiological evaluation in each case, was completed for 84 of the 115 infants referred (73%).

Eleven infants were identified with a sensorineural hearing loss,[3] six with bilateral severe-to-profound losses, four with unilateral severe-to-profound losses, and one with a unilateral moderate loss. It is important to emphasize that all data regarding hearing loss are based on results of a behavioral audiological evaluation that were confirmed on at least two separate occasions. Additionally, 37 infants were identified as having persistent fluctuating conductive hearing losses.[4] Thirty-one of these were bilateral conductive losses and six were

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[3]It should be noted that although the label of 'sensorineural hearing loss' is used throughout this article to refer to this group of 11 infants, one of the infants has a severe permanent structural hearing loss which may or may not have a sensorineural component. Because treatment techniques are the same in any case, this infant was included in this group for ease of reference.

[4]For purposes of these analyses, the operational definition of a persistent fluctuating conductive hearing loss was that, on two or more audiological evaluations separated by at least 4 weeks, the child exhibited hearing thresholds greater than 25 dB HL at two or more test frequencies, and abnormal tympanograms (flat or significantly negative middle-ear pressure).

unilateral.

Table 1 shows the prevalence of confirmed sensorineural and conductive hearing loss among various subsets of this sample. Not surprisingly, the

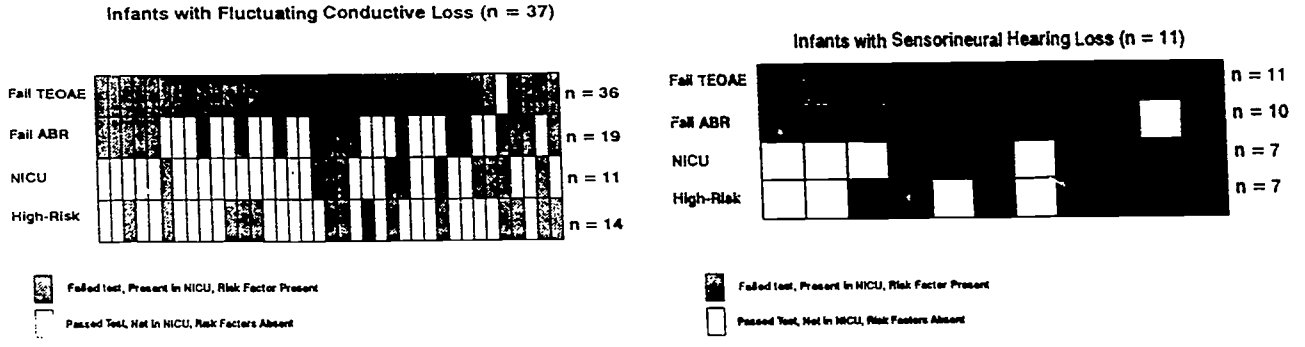
Table 1

	Total Sample (n = 1850)	Normal Nursery (n = 1546)	NICU (n = 304)
Conductive Hearing Losses	20.00	16.82	36.18
All Sensorineural Hearing Losses	5.95	2.59	23.03
Bilateral Severe/Profound Hearing Losses	3.24	1.29	13.16
Unilateral Moderate to Profound Hearing Losses	2.70	1.29	9.87
All Hearing Losses	25.95	19.41	59.21

prevalence of both conductive and sensorineural hearing losses among infants who were in the NICU is considerably higher than for infants who were in the normal nursery. It's important to note that a substantial number of infants with sensorineural hearing loss would have been missed if only infants in the NICU had been screened. Furthermore, the prevalence rate observed in this study for infants with bilateral severe-to-profound losses is markedly higher than prevalence rates for similar infants typically reported in the literature (e.g., Davis & Wood, 1992; Feinmesser, Tell, & Levi, 1986; Fitzaland, 1985; Parving, 1985).

Because ABR has been the most widely accepted method of identifying hearing loss in infants, we have compared the TEOAE and ABR results using three different approaches. First, for each of the infants identified as having a

sensorineural or fluctuating conductive loss, Figure 3 shows the results of the initial TEOAE and the initial ABR, the number of days spent in the NICU, and



whether the infant exhibited any of the high-risk factors for hearing loss identified by the Joint Committee for Infant Hearing (1990). As can be seen, all 11 infants with sensorineural losses failed the TEOAE at the initial screening, and 10 of them failed the ABR. Four of the infants were never in the NICU and four did not exhibit any of the high-risk indicators. For this sample, the TEOAE was the best predictor of sensorineural hearing loss. If ABR screening had been done only with infants in the NICU, or with infants who exhibited the high-risk indicators, as is the practice with most screening programs (Blake & Hall, 1990), 5 of the 11 infants with sensorineural hearing loss identified with TEOAE would have been missed.

Of the 37 infants identified with a fluctuating conductive hearing loss, 36 did not pass the TEOAE (15 of those were partial passes and 21 were fails).

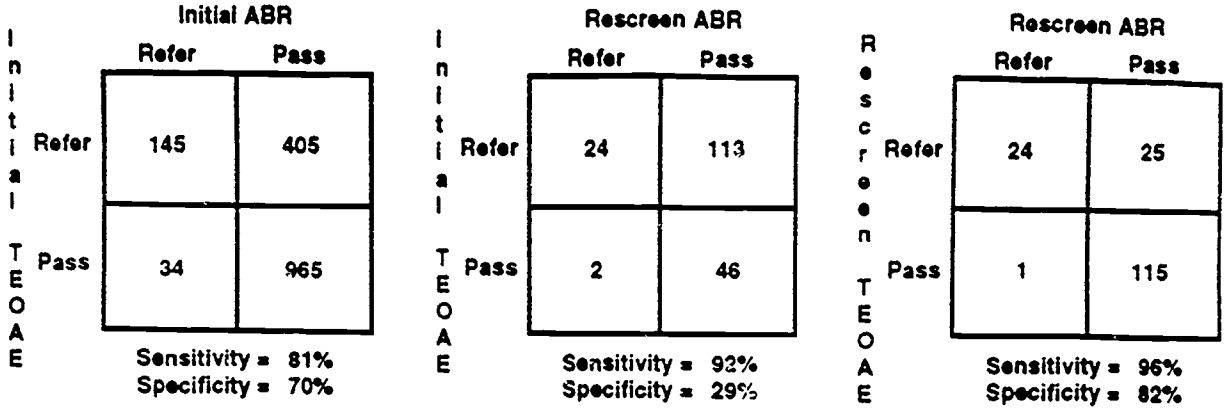
Only 19 of these infants would have been referred using ABR, only 11 were in the NICU, and only 14 exhibited any of the Joint Committee's high-risk indicators. If ABR screening had only been done of infants who were high risk, only 7 of the 37 would have been identified.

The information in Figure 3 clearly demonstrates the value of screening every live birth for hearing loss. It also shows that TEOAE is comparable to ABR for identifying sensorineural losses, but is better for identifying conductive losses. Further discussion about the use of TEOAE screening in identifying conductive hearing losses is given elsewhere in this issue by Maxon, White, Vohr, and Behrens (1993).

Another way of examining the agreement between TEOAE and ABR is to use the ABR result as the "gold standard" and compare the sensitivity/specificity of TEOAE with ABR. Figure 4 shows the relationship between ABR and TEOAE test results at both the initial screening and at the second stage of screening at the age of four to six weeks. A comparison of the initial ABR and

initial TEOAE results shows a sensitivity of 81% and a specificity of 70%. The comparison between rescreen ABR and initial TEOAE is even better with respect

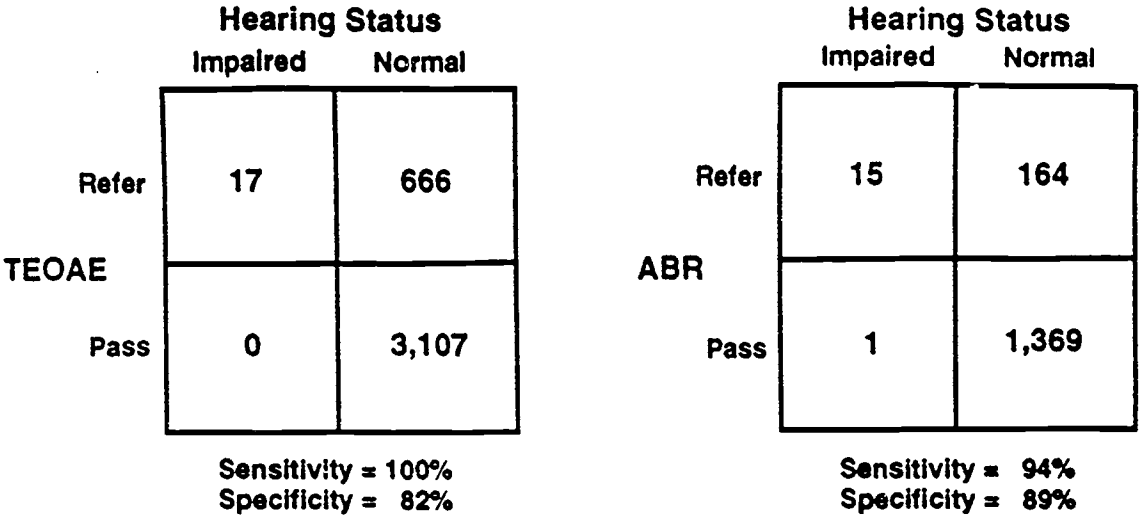
Figure 4



to sensitivity, and the comparison of rescreen ABR and rescreen TEOAE is excellent, with a sensitivity of 96% and a specificity of 82%.

A third way to evaluate the results of TEOAE and ABR is to compare each technique to confirmed sensorineural hearing loss at 6 to 12 months of age. In cases where infants who passed an initial screening do not receive further hearing evaluation, it is typically assumed that infants who passed the initial screening all have normal hearing (see, e.g., Dennis, Sheldon, Toubas, & McCaffee, 1984; Hyde et al., 1990; Stein, Ozdamar, Kraus, & Paton, 1983). Using this approach (which, although it is based on rather generous assumptions, uses the same basis of comparison for each technique), the results for both TEOAE and ABR are shown in Figure 5. As can be seen, sensitivity is excellent for both tests, but slightly better for TEOAE. Specificity is very good for both tests, but slightly better for ABR.

Figure 5



Although previous research has suggested that the measurement of TEOAE may be useful in newborn hearing screening, this study provides even stronger evidence. First, the number of infants on which the evidence is based is substantially larger for this study than in any previous study. Second, the inclusion of infants from both the normal nursery and the NICU, and the fact that a considerable number of infants with hearing impairments were identified from both settings, emphasizes the value of screening every live birth. Third, while most earlier evaluations of TEOAE screening compared TEOAE results with findings of ABR testing, this study has compared results of both TEOAE and ABR testing with behaviorally confirmed hearing loss. Finally, this study has demonstrated that TEOAE screening, has the potential for identifying persistent fluctuating conductive as well as sensorineural hearing losses (this is consistent with the suggestion made previously by Kennedy et al., 1991).

Because there was not complete agreement between the TEOAE and ABR

results, it is important to note that even though ABR is widely accepted as an effective means of identifying hearing loss in neonates, it is by no means perfect. For example, Murray et al. (1985), in a comprehensive review of 32 published studies of ABR screening for hearing loss in neonates, showed that only 32.3% of infants who failed an initial ABR, failed a retest several weeks or months later. Furthermore, there are reports in the literature of infants who, although they passed initial ABR testing, were later found to have significant sensorineural hearing loss. For example, Nield, Schrier, Ramos, Platzker, and Warburton (1986) reported on 11 high-risk infants with normal ABR results at the time of discharge from the NICU, who exhibited sensorineural hearing loss 13 to 48 months later. Thus, anyone comparing TEOAE and ABR results, where ABR is used as the standard, must keep in mind the substantial number of ABR false positives as well as the possibility of occasional false negatives when ABR is employed to screen neonates for hearing loss.

One of the goals of this Project was to evaluate the feasibility, validity, and cost efficiency of using TEOAE to do universal newborn hearing screening. The data collected at WIHRI clearly demonstrate that because of the simplicity and speed with which it can be implemented, it is feasible to use TEOAE as a hearing-screening tool for every live birth. The RIHAP study also confirms and extends results of previous research (e.g., Bonfils, Uziel, & Pujol, 1988; Stevens, Webb, Hutchinson, Connell, Smith, & Buffin, 1989, 1990; Uziel & Piron, 1991; Kennedy et al., 1991) in demonstrating that TEOAE accurately identifies

sensorineural hearing loss, and indicates those infants who are most at risk for conductive hearing losses. Finally, because TEOAE screening is relatively inexpensive[5], it is an economically viable technique to use in universal newborn hearing screening. Because it can be used to screen every live birth, TEOAE screening has the added advantage of identifying the substantial number of infants with hearing loss who do not have any of the high-risk factors identified by the Joint Committee on Infant Hearing.

In this context, however, it is important to emphasize that the use of TEOAE as a newborn hearing screening technique does not replace the need for ABR testing with infants. Although ABR can be used in screening, its most significant contribution to the early identification of hearing loss is in diagnostic evaluation, when used in conjunction with behavioral audiological techniques, to determine type, degree, and configuration of hearing loss. Expansion of newborn hearing-screening programs based on TEOAE will increase the need for both ABR and behavioral audiological evaluations to diagnose the actual hearing losses in infants identified by means of a TEOAE screening program.

In summary, the importance of identifying significant hearing impairment before 12 months of age has long been recognized. Not only does bilateral sensorineural hearing loss have a devastatingly negative effect on cognitive development, language acquisition, and life success, but recent research has

[5]A detailed cost analysis reported elsewhere in this issue by Johnson, Mauk et al., 1993, shows that the two stages of the newborn hearing screening costs approximately $20 per infant screened.

demonstrated that mild bilateral and unilateral losses can also have substantial negative effects on children's development of speech, cognition, and social skills. For example, Bess and Tharpe (1984) reported that 10 times as many children with unilateral hearing losses repeated a grade in school as children with normal hearing. Similar results have been reported by Bess, Klee, and Culbertson (1986) and Oyler, Oyler, and Matkin (1987). Unfortunately, effective techniques that have heretofore been available for such hearing screening among infants and young children have been too expensive and difficult to implement (e.g., ABR screening of every live birth), have missed significant numbers of hearing-impaired children (e.g., high-risk registries), or have not been available for very young children (e.g., behavioral screening programs such as those implemented in countries with socialized medicine through regular home health visitors).

Thus, to substantially reduce the average age at which significant hearing impairment is identified in the U. S., the use of better techniques than have previously been available will be needed. The data from the RIHAP study demonstrate that TEOAE screening of all newborns is such an approach. It is simple, fast, economical, non-invasive, and accurate in identifying more infants with sensorineural hearing loss than other available techniques. It has the added advantage of being able to identify a substantial number of infants who will develop persistent fluctuating conductive hearing losses. As demonstrated in this study, screening of every live birth with TEOAE can be incorporated into standard hospital practice and results in the identification of many more children

with hearing loss than current prevalence rates would suggest. As it is used more widely, further improvements in its efficiency are expected. Based on these results, transient evoked otoacoustic emissions should be seriously considered as a standard screening technique for all infants born in the United States.

Utah

Retrospective study. In 1989-1990, a retrospective study was undertaken by the Project to discover the patterns of identification of six- to nine-year-old children with educationally-significant, sensorineural hearing losses who were attending programs operated by the Utah School for the Deaf and who were born in Utah during the time that the birth certificate-based registry was in full operation. A listing of all children with educationally-significant sensorineural hearing losses (n=93) was obtained from the Utah School for the Deaf. Of the 93 parents/guardians on the interview list, 15 declined participation (16%), five had moved out of state prior to the survey and could not be located (5%), and three were parents of visually-impaired students who were erroneously listed on the hearing-impaired registry (4%). Thus, 78% (70 of the 90 children with hearing impairments) of the accessible population of parents/guardians of hearing-impaired, six- to nine-year-old children was interviewed.

Data were collected from parents/guardians of the children using a standardized phone interview protocol. In addition to questions about general demographic characteristics, the survey protocol contained questions pertaining to the suspicion, identification, and habilitation process that the parents had experienced as well as to the children's births and medical histories. Questions were posed in the

following areas: (a) neonatal risk status for hearing loss; (b) auditory-related behaviors observed (or not observed) by parents/guardians during their child's early months of life; (c) actions of the professionals whom parents first contacted because of concern for their child's hearing; (d) age of suspicion of hearing loss; (e) age of confirmation of hearing loss; (f) age of amplification; and (g) age of habilitation. Birth certificate information regarding neonatal risk factors on the total population was provided by the Utah Department of Health, Bureau of Communicative Disorders.

As can be seen in Table 2, only half of the sample of children exhibited any of the risk criteria recommended by the Joint Committee on Infant Hearing (1982). These data support the findings of Elssmann, Matkin, and Sabo (1987) who reported that 48% of children with sensorineural hearing losses exhibited high-risk characteristics and Stein, Clark, & Kraus (1983) who stated that 25% to 30% of hearing-impaired children do not exhibit such high-risk characteristics. The most frequently demonstrated Joint Committee risk factor in the present study was family history of hearing loss (29%).

Table 2 Potential detection rate of the current Joint Committee on Infant Hearing high-risk register for hearing loss.

Risk Status	*n*	Percent
High-risk	35	50
Not high-risk	35	50

In the present study, 57% of the parents reported that their child was in a NICU immediately following birth (this figure is substantially higher than the 33% figure reported by Elssmann et al., 1987). If admittance to a NICU had been included as a risk factor with this sample, then 9 of the 35 children (26%) who were missed by the other risk factors would have been included. Including NICU admission as a risk factor would mean that 63% of children with sensorineural hearing losses in the sample would have been identified as high-risk.

Another relevant issue is that of appropriate and aggressive follow-up of children who exhibit risk factors predictive of hearing impairment. In this sample of parents of high-risk children who actually had sensorineural hearing losses, only 33% of the parents requested an appointment for a hearing evaluation, when they were contacted by the State's Bureau of Communicative Disorders. Most of the parents did not respond to the mailer or reported having no concerns about their children's hearing (22%), could not be located in the records of the Bureau of Communicative Disorders (19%), or responded that their child had been already tested audiologically (26%). Even among those parents who requested testing, only about one-third actually followed through and arrived for the appointment (Mahoney & Eichwald, 1986).

Table 3 lists, by degree of hearing loss of the child, the percentage of parents who noticed auditory behavior deficits in their children at three age ranges. As would be expected, the greater the degree of hearing loss and the older the age of the child, the more parents noticed that their children were not exhibiting developmentally-

appropriate, auditory-related behaviors. In this study, about 40% of the parents of children with moderate to profound hearing losses notice behavioral indicators of hearing loss between birth and 3 months of age and continue to observe them. However, many parents (21%-36%) of children with mild-moderate hearing losses (25-55 dB HL) began to notice when the child was relatively young (6 to 12 months of age) that their child was not responding to environmental sounds nor comprehending words which were common for the children's age.

Table 3

Severity of hearing loss and developmental auditory behavior deficits observed by parents.

Auditory Behavior Deficit	Expected Age Range (in mo)	Percentage of Parents By Degree of Hearing Loss[a]
Did not startle or jump when there was a sudden loud sound	Birth–3	0—Mild-Moderate 41—Moderate-Severe (n = 11) 40—Profound (n = 11)
Did not stir or awaken from sleep or cry when someone talked or made a noise	Birth–3	7—Mild-Moderate (n = 1) 37—Moderate-Severe (n = 10) 40—Profound (n = 11)
Did not recognize and was not comforted by a familiar voice	Birth–3	7—Mild-Moderate (n = 1) 19—Moderate-Severe (n = 5) 31—Profound (n = 9)
Did not turn eyes to look for an interesting sound	3–6	14—Mild-Moderate (n = 2) 44—Moderate-Severe (n = 12) 45—Profound (n = 13)
Did not respond to mother's or caregiver's voice	3–6	7—Mild-Moderate (n = 1) 41—Moderate-Severe (n = 11) 35—Profound (n = 10)
Did not turn eyes forward when name was called	3–6	21—Mild-Moderate (n = 3) 44—Moderate-Severe (n = 12) 45—Profound (n = 13)
Did not turn toward interesting sound or toward caregiver when name was called from behind	6–12	29—Mild-Moderate (n = 4) 67—Moderate-Severe (n = 18) 48—Profound (n = 14)
Did not understand "No" and "Bye Bye" and similar common words	6–12	21—Mild-Moderate (n = 3) 52—Moderate-Severe (n = 14) 45—Profound (n = 13)
Did not search or look around when new sounds were present	6–12	36—Mild-Moderate (n = 5) 59—Moderate-Severe (n = 16) 35—Profound (n = 10)

[a] *Total n mild-moderate = 14; total n moderate-severe = 27; total n profound = 29.*

Table 4 illustrates the importance of parental awareness of behaviors related to hearing loss. For parents who first noticed that their children were not demonstrating normal auditory awareness between birth and 3 months of age, the mean age of suspicion was 5 1/2 months; for parents who did not first suspect that their child had a hearing problem until between 6 and 12 months of age, the mean age of suspicion more than doubled to an average of 13.7 months. Even more disturbing is the fact

Table 4

Auditory deficit behaviors noticed first by parents and mean age of suspicion of hearing loss.

Number/Percent of Parents	Age Range of Auditory Behaviors Noticed First	Mean Age of Suspicion (mo)
24/34%	Birth–3 mo	5.5
9/13%	3–6 mo	9.8
11/16%	6–12 mo	13.7
26/37%	No behavior noticed first	18.9

that for parents who did not first notice any auditory behavior-related deviation in their children, the mean age of suspicion was approximately 19 months.

Table 5 contains a comparison of the identification histories of children who exhibit high-risk characteristics and those who do not, from the average age at which parents first suspected that their child had a hearing loss until the average age at which the child first entered habilitative services (e.g., parent-infant program, speech/language therapy). These results indicate that parents of high-risk children, on average, suspect a problem approximately 5 months earlier, obtain a

hearing test approximately 7 months earlier, have their child's hearing loss confirmed approximately 8 months earlier, have their child fitted with amplification devices and enroll their child in habilitative services approximately 5 months earlier than parents of children with no risk factors for hearing loss.

Table 5

Comparison of high-risk and not high-risk children from mean age of suspicion of hearing loss until mean age of services

Historical Identification Events	Utah Department of Health and Retrospective Survey Data[a] (Mean Age in mo)
High-risk[b]	(n = 35)
Age of suspicion of hearing loss	9.9
Age of first hearing test	11.3
Age of confirmation of hearing loss	12.8
Age of first amplification	17.1
Age of first services	18.2
Not high-risk[c]	(n = 35)
Age of suspicion of hearing loss	14.8
Age of first hearing test	18.7
Age of confirmation of hearing loss	20.5
Age of first amplification	22.6
Age of first services	23.1

[a] A total of 70 children with Utah Department of Health risk data and parent survey reports of risk (Utah births only)
[b] Child was reported to have at least one Joint Committee risk factor for hearing impairment
[c] Child was reported to have no Joint Committee risk factor for hearing impairment

Table 6 illustrates the effects of placation and referral by primary care providers on the mean age of suspicion and confirmation of hearing loss. On average, children benefited immensely from appropriate referral by primary care providers, whether or not they exhibited high-risk characteristics. Whereas the average delay from suspicion until confirmation of hearing loss for high-risk children who were referred was 1.7 months, the average delay for the placated group, was 8.3 months. Likewise, the average delay for not high-risk children who were referred by primary care providers was 4.9 months, while the delay for the placated group was 8.2 months.

Table 6

Effects of referral (good advice) and placation (poor advice) by primary care providers on mean age of suspicion and mean age of confirmation of hearing loss.

Category	Mean Age of Suspicion of Hearing Loss (mo)	Mean Age of Confirmation of Hearing Loss (mo)	Average Delay from Suspicion to Confirmation of Hearing Loss (mo)
High-risk			
Referred (n = 28)	9.7 (S.D. = 11.2)	11.4 (S.D. = 11.2)	1.7 (S.D. = 2.8)
Placated (n = 7)	10.4 (S.D. = 8.1)	18.7 (S.D. = 16.4)	8.3 (S.D. = 11.8)
Not high-risk			
Referred (n = 27)	16.3 (S.D. = 13.1)	21.2 (S.D. = 13.1)	4.9 (S.D. = 6.4)
Placated (n = 8)	9.8 (S.D. = 11.5)	18.0 (S.D. = 9.8)	8.2 (S.D. = 7.4)

The results of an analysis of the effects of the degree of hearing loss on age of confirmation are presented in Table 7. These results suggest that children born with profound hearing losses had their losses confirmed, on average, between 8 months (high-risk) and 18 months (not high-risk) of age, as compared with 12 months (high-risk) and 17 months (not high-risk) of age for those with moderate to severe losses. Average ages of confirmation for children with mild to moderate losses ranged from 19 months (high-risk) to 38 months (not high-risk). These data are a confirmation of the inverse relationship between age of confirmation and degree of hearing loss reported previously (Elssmann et al., 1987; Malkin, Freeman, & Hastings, 1976; Shah et al., 1978).

Table 7

Degree of hearing loss, risk status and mean age at confirmation of hearing loss.

Degree of Hearing Loss		Mean Age at Confirmation (mo)	n
Mid to moderate (25–55 dB HL)	High-risk	19.2	10
	Not high-risk	38.5	4
Moderate to severe (56–90 dB HL)	High-risk	12.3	11
	Not high-risk	17.8	16
Profound (>90 dB HL)	High-risk	8.7	14
	Not high-risk	18.5	15
All losses	High-risk	12.8	35
	Not high-risk	20.5	35

The results of this retrospective study confirmed that properly implemented birth certificate-based high-risk registers are a feasible and effective means of identifying children with educationally-significant, sensorineural hearing impairment at an early age. Based on the factors recommended by the Joint Committee on Infant Hearing (1982), half of the children with educationally-significant sensorineural losses in the present study would be identified by such a system. Regarding the issue of relevant risk criteria for sensorineural hearing loss, previous studies have reported that the incidence of hearing loss among neonatal intensive care unit (NICU) graduates might be as high as 7% (Galambos, Hicks, & Wilson, 1982; Schulman-Galambos & Galambos, 1979; Stein, Ozdamar et al., 1983). In the present study, 57% of the parents reported that their child was in a NICU immediately following birth (figure is substantially higher than the 33% figure reported by Elssmann et al., 1987). If admittance to a NICU had been included as a risk factor with this sample, then 9 of the 35 children (26%) who were missed by the other risk factors would have been included, raising percentage of at-risk children with sensorineural hearing losses in the sample from 50% to 63%. Since data about admission to a NICU are much easier to collect than data about many of the other risk factors, it seems wise to add this variable as a high-risk factor for hearing impairment.

However, it is clear from this study that based on current knowledge, the use of a high-risk registry is not enough. It is important to emphasize that even though the systematic identification and screening of children exhibiting high-risk factors would result in many children with sensorineural hearing losses being identified

earlier, almost 40% of hearing-impaired children do not exhibit any of these risk factors and many of the children who do exhibit high-risk characteristics do not come in for further diagnostic testing. These findings suggest the need for continued attention to regular hearing screenings up to and including the first years of formal education. Furthermore, even the best high-risk screening registry must be operated in conjunction with alert and well-educated parents and physicians, if hearing impairment is to be identified as early as it should be (Elssmann et al., 1987; Jacobson & Jacobson, 1990).

The successful implementation of screening programs to identify children with sensorineural hearing losses requires knowledge about the risk factors associated with hearing loss, design of screening programs which are feasible to implement and capable of identifying children who have those risk factors, and successful and appropriate follow-up of children exhibiting risk factors (Jacobson & Jacobson, 1990). Despite advances in early identification of hearing loss, without adequate follow-up services, hearing screening programs such as birth certificate-based registries will continue to fall short of the objective of identifying all significant hearing losses before 12 months of age. To provide the intervention and management strategies necessary to enable children with significant sensorineural losses to make optimal developmental progress, a combination of strategies is needed including effective screening based on high-risk criteria, parent involvement, appropriate diagnostic testing, and education of health care professionals. Attention to such strategies would substantially reduce the average age at which children in the United States with

significant sensorineural hearing losses are identified.

High-risk registry "non-respondent survey." In April, 1991, a survey of non-respondents to the birth certificate-based high risk registry program was conducted by Utah Bureau of Communicative Disorders with the assistance of the Project (Mahoney, Eichwald, & Fronberg, 1992). Out of the 23,409 Utah live births between January and July 1990, 1,722 (7.4%) parents were sent high risk hearing notifications with accompanying response cards. Of 734 (45%) who did not respond, 106 were randomly selected to participate in a telephone survey (out of which 103 were able to complete the phone survey). The five-minute phone survey was designed to investigate potential reasons why parents did not respond to the high risk notices by returning the parent response card. Six questions/items comprised the survey. Three of the questions/items had a number of prompts that were asked by the interviewer when there was no parent-generated response occurred to the open-ended inquiry. The summarized results immediately follow each question/item:

(1) "Do you recall receiving either of these cards?" [95 parents (92%) said "Yes;" 8 parents (8%) said "No" (those parents who responded "No" received appropriate early identification information and were not questioned further)];

(2) "There are a number of reasons why people may not respond to a mailing such as this. Please tell me why you did not respond." [Seventy parents (74%) responded with only one reason; 25 parents (26)% responded with two reasons; One parent (1%) offered three reasons. Forty-seven parents (49%) responded by saying there was nothing wrong with their child's hearing. Twenty-three parents (24%) said

they forgot to return the response card. Twenty-one parents (22%) responded that they already had their child's hearing evaluated. Eight parents (8%) indicated that the family history of hearing loss information was incorrect. Five parents (5%) stated that the advice they received from their doctor led them not to respond. Three parents (3%) were concerned that they might have to pay for the hearing testing and one parent (1%) reported that she did not understand the card.];

(3) "Did you talk to your child's doctor about the high-risk card?" [Eighty-two of the parents (86%) said "No;" 13 parents (14%) responded "Yes." Those parents answering "Yes" were asked, "What did the doctor say?" Seven parents (54%) reported that the doctor told them not to worry about it. Two parents (15%) reported that their physicians told them the child was not at-risk.];

(4) "Did you understand why your child may have been high risk for hearing loss?" [Seventy-five parents (79%) responded "Yes;" 20 parents (21%) answered "No." Those parents answering "No" were asked, "Which high-risk items did you not understand?" Ten parents (50%) said they did not understand "Apgar score." Eight parents (40%) said they did not understand "family history." Two parents (10%) did not understand "illness or condition of pregnancy" and one parent (5%) did not understand "asphyxia."];

(5) "Do you remember reading the hearing checklist on the yellow card mailed with your notice?" [Sixty parents (63%) remembered the card and 35 parents (37%) did not remember the card. Those parents answering "Yes" were asked, "Did the checklist influence your decision not to return the card?" Twenty-seven parents

(45%) felt the checklist did influence their decision to return the card; 33 parents (55%) did not feel that the checklist influenced their decision.]; and

(6) "Are you concerned about your child's hearing at the present time?" [20 parents (21%) said "Yes;" 75 parents (79%) said "No." Seventeen of the concerned parents (85%) arranged for a hearing test and eight (11%) parents who said they were not currently concerned about their child's hearing requested a hearing test.

The implications of this programmatic evaluation for birth certificate-based hearing screening using a high-risk registry are explicated in Mahoney et al. (1992).

Ethnic/Racial Groups Directly Affected by the Project

1990 U.S. Census Data for Affected States/Persons
(U.S. Department of Commerce, 1991)

POPULATION CATEGORY	STATE AND NUMBER/PERCENT OF PERSONS	
	OREGON	RHODE ISLAND
Total Population	2,842,321 (100%)	1,003,464 (100%)
Males	1,397,073 (49.2%)	481,496 (48.0%)
Females	1,445,248 (50.8%)	521,968 (52.0%)
White	2,636,787 (92.8%)	917,375 (91.4%)
Black	46,178 (1.6%)	38,861 (3.9%)
American Indian, Eskimo, or Aleut	38,496 (1.4%)	4,071 (0.4%)
Asian or Pacific Islander	69,269 (2.4%)	18,325 (1.8%)
Other Race	51,191 (1.8%)	24,832 (2.5%)
Hispanic Origin (of any race)	112,707 (4.0%)	45,752 (4.6%)

Based on the above data and given that the approximate number of births per year in the states of Oregon and Rhode Island are 40,000 and 17,000, respectively, the approximate number and percentages of babies from the respective population categories were served. Note that the Oregon figures are based on the approximately 10% of the infant population which has manifests at least one risk factor for hearing loss (n = 4,000 births) and the Rhode Island figures are based on the approximately 10,000 infants born annually at Women and Infants Hospital in Rhode Island. No infants in Utah were served directly, although refinements and modifications, if any, made in the birth certificate-based high-risk as a result of retrospective research may positively impact future youth.

POPULATION CATEGORY	STATE AND NUMBER/PERCENT OF BABIES	
	OREGON	RHODE ISLAND
Births per Year	4,000 (100%)	10,000 (100%)
Males	1,968 (49.2%)	4,800 (48.0%)
Females	2,032 (50.8%)	5,200 (52.0%)
White	3,712 (92.8%)	9,140 (91.4%)
Black	640 (1.6%)	390 (3.9%)
American Indian, Eskimo, or Aleut	560 (1.4%)	40 (0.4%)
Asian or Pacific Islander	960 (2.4%)	180 (1.8%)
Other Race	720 (1.8%)	250 (2.5%)
Hispanic Origin (of any race)	160 (4.0%)	460 (4.6%)

VI. PUBLICATIONS/PRODUCTS

Publications

Mauk, G., White, K. R., Mortensen, L., & Behrens, T. R. (1991). The effectiveness of screening programs based on high-risk characteristics in early identification of hearing impairment. Ear and Hearing, 12, 312-319.

White, K. R., Maxon, A. B., Behrens, T. R., & Blackwell, P. (1992). An evaluation of neonatal hearing screening using evoked otoacoustic emissions: Preliminary results of the Rhode Island Hearing Assessment Project. In F. Bess, Screening children for auditory function. Nashville, TN: Bill Wilkerson Center Press, 207-228.

White, K. R., Vohr, B. R., & Behrens, T. R. (1993). Universal newborn hearing screening using transient evoked otoacoustic emissions: Results of the Rhode Island Hearing Assessment Project. Seminars in Hearing, 14(1).

Maxon, A. B., White, K. R., Vohr, B. R., & Behrens, T. R. (1993). The feasibility of identifying risk for conductive hearing loss in a newborn universal screening program. Seminars in Hearing, 14(1).

Vohr, B. R., White, K. R., Maxon, A. B., & Johnson, M. J. (1993). Factors affecting the interpretation of transient evoked otoacoustic emission. Seminars in Hearing, 14(1).

Mauk, G. W., Behrens, T. R. (1993). Historical, political, and technological context associated with early identification of hearing loss. Seminars in Hearing, 14(1).

Johnson, M. J., Maxon, A. B., White, K. R., & Vohr, B. R. (1993). Operating a hospital-based universal newborn hearing screening program using transient evoked otoacoustic emissions. Seminars in Hearing, 14(1).

Kemp, D. T., & Ryan, S. (1993). The use of transient evoked otoacoustic emissions in neonatal hearing screening programs. Seminars in Hearing, 14(1).

Brackett, D., Maxon, A. B., Blackwell, P. M. (1993). Intervention issues created by successful universal newborn hearing screening. Seminars in Hearing, 14(1).

Johnson, J. L., Mauk, G. W., Takekawa, K. M., Simon, P. R., Sia, C. J., Blackwell, P. M. (1993). Implementing a statewide system of services for infants and toddlers with hearing disabilities. Seminars in Hearing, 14(1).

Publications (continued)

Moore, W. G., Josephson, J. A., & Mauk, G. W. (1991). Identification of children with hearing impairments: A baseline survey. The Volta Review, 93(4), 187-196.

Josephson, J. A. (1991, Summer). Can your baby hear? That's my baby, 14-15, 53.

Examples of Presentations

White, K. R., Maxon, A. B., & Johnson, M. J. (August 10, 1992). Neonatal screening for hearing impairment using evoked otoacoustic emissions (EOAE). Paper presented at the Fourth International Congress of Hard of Hearing People, Jerusalem, Israel.

White, K. R. (August 31, 1992). Current issues of early identification, diagnosis, and management of young hearing-impaired children. Invited presentation to XXI International Congress of Audiology, Morioka, Japan.

White, K. R. (May 11, 1991). The Rhode Island Hearing Assessment Project: Design, Findings, and Implications. Paper presented at the International Conference, Otoacoustic Emissions: Theory, Applications, and Techniques, Kansas City.

White, K. R. (April 25, 1991). The use of otoacoustic emissions in a hospital-based screening program to identify hearing loss in young children. Keynote address presented to The National Hearing Screening Networking Conference, Baltimore, Maryland.

Mortensen, L. B., & Mauk, G. W. (1991, June). Evoked otoacoustic emissions technology: Principles, application, and demonstration. Poster presented at the 72nd Annual Meeting of the Pacific Division of the American Association for the Advancement of Science, Logan, UT.

Mortensen, L. B., & Mauk, G. W. (1991, May). Temporal, stimulus, and child parameters of OAE screening results in a neonatal population. Poster presented at the International Symposium on Otoacoustic Emissions: Theory, Techniques, and Application, Kansas City, MO.

Mauk, G. W., & White, K. R. (1990, May). Retrospective survey of identification of hearing impairment in children. Paper presented at the bi-annual conference of the Utah Speech-Language-Hearing Association, Park City, UT.

Examples of Presentations (continued)

Maxon, A. B., Norton, S. J., White, K. R., & Behrens, T. R. (November 22, 1991). Evoked otoacoustic emissions in neonatal screening and follow-up: Clinical trials. Seminar (1/2 day) presented at the annual meeting of the American Speech-Language-Hearing Association, Atlanta, Georgia.

Vohr, B. R., White, K. R., Behrens, T., and Blackwell, P. (April 1991). Auditory screening of neonates using otoacoustic emissions. Paper presented at the annual meeting of the Academy of Audiology. Denver, Colorado.

Vohr, B. R., White, K. R., Kemp, D., & Blackwell, P. (October, 1990). Auditory screening for neonates using otoacoustic emissions. Paper presented at the XXth International Congress of Audiology Tenerife, Canary Islands, Spain.

White, K. R., & Behrens, T. R. (January 13, 1992). Newborn hearing screening using otoacoustic emissions. Invited presentation to the Third Annual Hawaii Early Intervention Conference, Honolulu, Hawaii.

White, K. R. (October 9, 1990). The Rhode Island Hearing Assessment Project: A clinical trial of the use of otoacoustic emissions to identify hearing loss in neonates. Invited paper presented at The Otoacoustic Emission and Early Identification of Hearing Impairment Symposium sponsored by the National Institute of Disability and Rehabilitation Research, Providence, Rhode Island.

Products

VIDEOTAPE: "Early identification of hearing loss." (1992). Oregon Newborn Hearing Registry, Portland, OR and Teaching Research, Western Oregon State College, Monmouth, OR. (Contents: An overview of the importance of early identification of hearing impairment is presented. Some results from Oregon's retrospective study of hearing impairment in children are presented and components of Oregon's birth certificate-based high-risk registry are described.)

VIDEOTAPE: "Early identification of hearing impairment in children." (1989). Utah State University, Department of Psychology, Early Identification of Hearing Impairment in Children Project. (Contents: An overview of the importance of early identification of hearing impairment is presented. The birth certificate-based high-risk registry operated by the Utah Bureau of Communicative Disorders is described.)

Appendix A

Materials Developed by the Project

Teaching Research Division

A state, regional, and national mission of research and program development.

OREGON NEWBORN HEARING REGISTRY:

A STATE WIDE SYSTEM TO LOWER THE AGE OF IDENTIFICATION AND HABILITATION OF INFANTS WITH HEARING IMPAIRMENTS

Goals:

1. to identify infants at risk for hearing loss and to notify their parents of the need for hearing screening;

2. to refer parents and health care professionals to local audiologists for reliable hearing screening;

3. to inform the community of early identification issues and available resources;

4. to evaluate the effectiveness of birth-certificate based screening.

PRESENTATION TO DIRECTORS OF SPEECH AND HEARING PROGRAMS IN STATE HEALTH AND WELFARE AGENCIES, INC.

ATLANTA, GEORGIA
NOVEMBER 1991

Western Oregon State College

ice: (503) 838-8391 • FAX: (503) 838-8150 • TDD (503) 838-8821
nmouth, OR 97361

OREGON NEWBORN HEARING REGISTRY
PROJECT DESCRIPTION

Rationale

In 1988 the Commission on Education of the Deaf reported to Congress that to improve educational outcomes for hearing-impaired people, the age at which children are identified as hearing-impaired must be lowered. The average age of identification in the United States is about 2½ years. A May, 1990 survey reports that the age of identification in Oregon is 30 months. In areas where there are systematic screening procedures (Utah, Colorado, Israel, Great Britain) the average age of identification is between 7 and 17 months.

The Office of Maternal and Child Health funded a project in Oregon to replicate the Utah model of birth certificate screening for risk factors for hearing loss for the purpose of lowering the age of identification. The grant is administered through Teaching Research at Western Oregon State College.

Procedures

The Oregon State Health Division screens birth certificates for risk factors for hearing loss. About 10.8 percent of the newborn population is at risk. When their babies are about 5 months old, parents of high-risk infants receive a notice from the Health Division explaining that the infants are at higher-than-normal risk for hearing impairment. The notice describes the program and offers parents several options for participation. Those wishing assistance in arranging an audiological screening will be contacted by their county public health nurse. A directory of licensed audiologists who have agreed to participate in the program is provided to each health department.

Once the infants' hearing has been evaluated, the audiologists systematically report their findings to the State Health Division, to local health departments and to family physicians. Audiologists use their usual procedures for billing. Adult and Family Services covers the initial screening cost for their clients who are referred by this project. CDRC sees infants for an initial eligibility determination visit (diagnosis) at no "out-of-pocket" expense to the family. More than 80 percent of the participating audiologists provide free hearing screening for families who have no means of payment.

There are excellent services available to hearing-impaired infants and their families in all parts of the state. The Oregon Newborn Hearing Registry provides information about these services to parents or guardians of newly identified hearing-impaired infants, to audiologists, to public health departments and to physicians.

For more information about the Registry, you may contact either one of the following individuals:

Jean Josephson, Project Director
771-3259
Portland, OR

Wm. Moore, Project Analyst
838-8794
Monmouth, OR

53

10.8 perc.

OREGON DEPARTMENT OF HUMAN RESOURCES
HEALTH DIVISION
Vital Records Unit
CERTIFICATE OF LIVE BIRTH

SAMPLE

136-

SAMPLE

CHILD — CHILD—NAME First Middle Last; SEX; DATE OF BIRTH; TIME OF BIRTH; FACILITY—NAME; CITY, TOWN, OR LOCATION OF BIRTH; COUNTY OF BIRTH

CERTIFIER — 5a. SIGNATURE; DATE SIGNED; CERTIFIER—NAME AND TITLE; NAME AND TITLE OF ATTENDANT AT BIRTH IF OTHER THAN CERTIFIER; ATTENDANT MAILING ADDRESS; DATE FILED BY REGISTRAR; REGISTRAR—SIGNATURE

MOTHER — MOTHER—NAME First Middle Last; MAIDEN SURNAME; DATE OF BIRTH; STATE OF BIRTH (If not in U.S.A., name country); RESIDENCE—STATE; COUNTY; CITY, TOWN, OR LOCATION; STREET AND NUMBER; INSIDE CITY LIMITS (Yes or no); ZIP CODE; MOTHER'S MAILING ADDRESS AND ZIP CODE

FATHER — FATHER—NAME First Middle Last; DATE OF BIRTH; STATE OF BIRTH (If not in U.S.A., name country)

INFORMANT — I certify that the personal information provided on this certificate is correct to the best of my knowledge and belief. (Signature of Parent or other informant)

ITEM CORRECTED: CORRECTED TO READ: DOCUMENTARY EVIDENCE: REVIEWED BY

INFORMATION FOR MEDICAL AND HEALTH USE ONLY

12. Shall abstract of birth certificate be made available for publication or business contact lists? No / Yes
13. Social Security Number Requested? No / Yes
14. OF HISPANIC ORIGIN? 15. RACE 16. EDUCATION 17. MOTHER MARRIED? HAS A CLOSE RELATIVE OF THIS NEWBORN HAD A HEREDITARY HEARING LOSS THAT EXISTED SINCE CHILDHOOD?

MOTHER / **FATHER**

APGAR SCORE 24 / 10 — 21 BIRTH WEIGHT 2.15 ...

21. PREGNANCY HISTORY — LIVE BIRTHS; OTHER TERMINATIONS; DATE OF LAST LIVE BIRTH; DATE OF LAST OTHER TERMINATION; 22. CLINICAL ESTIMATE OF GESTATION
23. DATE LAST NORMAL MENSES BEGAN; 24a. PLURALITY; 24b. IF NOT SINGLE BIRTH; 25. MONTH OF PREGNANCY PRENATAL CARE BEGAN; 26. PRENATAL VISITS
27. SITE—PRENATAL CARE; 28. PRIMARY FINANCIAL COVERAGE OF THIS DELIVERY
29. AT TIME OF THIS REPORT WAS NEWBORN ALIVE? NEWBORN REQUIRED INTERMEDIATE OR INTENSIVE CARE? Yes ✓; NEWBORN TRANSFERRED FOR MEDICAL NEED? Yes ✓; 32. MONTHS MOTHER ON WIC PROGRAM

33. MEDICAL FACTORS FOR THIS PREGNANCY — Other (Specify) all maternal ...
34. COMPLICATIONS OF LABOR AND/OR DELIVERY — Other (Specify) severe asphyxia
35. OTHER FACTORS FOR THIS PREGNANCY
36. ANTENATAL PROCEDURES
37. INTRAPARTUM PROCEDURES
CONDITIONS OF THE NEWBORN — Other (Specify) jaundice 774...
38. METHOD OF DELIVERY
40. CONGENITAL ANOMALIES OF NEWBORN — Other (Specify) ...

33.
ICD-9 Codes
760.2
771.0-
771.2
771.8

40. Persistent Fetal Circulation
747.0 in other or 07

severe 768.5 090 Cong. syphilis meningitis 320.0-322 774.7 744.0-744.9

BEST COPY AVAILABLE

OREGON NEWBORN HEARING REGISTRY

RISK FACTORS FOR HEARING IMPAIRMENT

FAMILY HISTORY OF HEARING IMPAIRMENT
LOW BIRTH WEIGHT (less than 1500 gms.)
5 MINUTE APGAR LESS THAN 6
CONDITIONS OF THE NEWBORN:
- cleft palate
- assisted ventilation for more than 30 minutes
- fetal alcohol syndrome
- meconium aspiration syndrome
- other central nervous system anomalies

ADMITTED TO ICU
NEWBORN TRANSFERRED FOR MEDICAL NEED

ICD-9 CODES FOR ADDITIONAL RISK FACTORS

760.2 MATERNAL INFECTIONS
771.0 CONGENITAL RUBELLA
771.1 CONGENITAL CYTOMEGALOVIRUS INFECTION
771.2 OTHER CONGENITAL INFECTIONS
- herpes simplex
- listeriosis
- malaria
- toxoplasmosis
- tuberculosis

771.8 OTHER INFECTION SPECIFIC TO THE PERINATAL PERIOD
Intraamniotic infection of fetus:
- NOS
- Clostridial
- Escherichia coli
- Intrauterine sepsis of fetus
- Neonatal urinary tract infection
- Septicaemia (sepsis) of newborn

774.0-774.7 OTHER PERINATAL JAUNDICE
320.0-320.9 BACTERIAL MENINGITIS
321.0-321.8 MENINGITIS DUE TO OTHER ORGANISMS
322.0-322.9 MENINGITIS OF UNSPECIFIED CAUSE
090 CONGENITAL SYPHILIS
768.5 SEVERE BIRTH ASPHYXIA
774.0 - 774.9 ANOMALIES OF THE EAR, FACE AND NECK
747.0 PATENT DUCTUS ARTERIOSUS

JAJ P.II 9/91

55

(503)
FAX (503)
TDD-Nonvoice (503) 229-6741

Oregon

1-800-723-3638 (1-800-SAFENET)

DEPARTMENT OF HUMAN RESOURCES

HEALTH DIVISION

11/12/91

To the Parents of:
Name
Address
City, OR 99999

DOB: 00/00/00

The following information on your baby's birth certificate suggests that your baby may have a higher chance than many babies of having a hearing loss:
History of Hearing Loss Low Birthweight

This does NOT mean that your baby has a hearing loss. The chance of your baby's involvement is very small, but we suggest that you have your baby's hearing checked by an audiologist, a person trained to measure hearing ability.

IF YOU HAVE ANY QUESTIONS, phone 1-800-723-3638 (1-800-SAFENET).

Please mark ONE selection below and return this form to our office.

[ ] 1. Please contact me about having my baby's hearing tested. (A public health nurse will call you to help make an appointment).

Name_____(please print)
Signature_____
Daytime phone_____

[ ] 2. I will make an appointment to have my baby's hearing tested by an audiologist. (If your baby was born prematurely, be sure to tell the audiologist so that the appropriate test date can be arranged.)

[ ] 3. My baby's hearing has already been tested by:
Name:_____
Address:_____
Results: passed_____ did not pass_____

[ ] 4. I do not want my baby to have a hearing test.

[ ] 5. The information on the birth certificate is incorrect.

PLEASE RETURN AS SOON AS POSSIBLE. (NBHR Form 9999999)

Barbara Roberts
Governor

1400 SW 5th Avenue
Portland, OR 97201
(503) 229-5599 Emergency
(503) 252-7978 TDD
Emergency

24-26 (Rev. 1-91)

(503)
FAX (503)
TDD-Nonvoice (503) 229-6741

1-800-723-3638 (1-800-SAFENET)

Oregon

DEPARTMENT OF
HUMAN
RESOURCES

HEALTH DIVISION

11/12/91

To the Parents of:
Name
Address
City, OR 99999

DOB: 00/00/00

Information on your baby's birth certificate (a family history of hearing loss) suggests that your baby might have a higher chance than many babies of having a hearing loss. A family history of hearing loss means that a close relative--mother, father, sister, brother, uncle, aunt, grandparents or first cousin--has a hereditary hearing loss and has needed to wear hearing aids since childhood.

This does NOT mean that your baby has a hearing loss. The chance of your baby's involvement is very small, but we suggest that you have your baby's hearing checked by an audiologist, a person trained to measure hearing ability.

IF YOU HAVE ANY QUESTIONS, phone 1-800-723-3638 (1-800-SAFENET).

Please mark ONE box below and return this form to our office.

[ ] 1. Please contact me about having my baby's hearing tested. (A public health nurse will call you to help make an appointment).

Name_____(please print)
Signature_____
Daytime phone_____

[ ] 2. I will make an appointment to have my baby's hearing tested by an audiologist.

[ ] 3. My baby's hearing has already been tested by:
Name:_____
Address:_____
Results: passed_____ did not pass_____

[ ] 4. I do not want my baby to have a hearing test.

[ ] 5. The family history of hearing loss information on the birth certificate is not correct.

PLEASE RETURN AS SOON AS POSSIBLE. (NBHR Form 9999999)

Barbara Roberts
Governor

1400 SW 5th Avenue
Portland, OR 97201
(503) 229-5599 Emergency
(503) 252-7978 TDD
Emergency

24-26 (Rev. 1-91)

WHERE YOU CAN HAVE YOUR BABY'S HEARING TESTED

You may contact any of these audiologists who test infants

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Portland Metropolitan Area

CLACKAMAS

Gary E. McClellan
1515 7th St., Suite A
Oregon City, OR 97405
656-0601
Hours: 9:15-12; 2-4:30 M-F
Initial screening fee: $27.50

Gloria Schnell
Mt. Scott Medical Clinic
9800 SE Sunnyside Rd.
Clackamas, OR 97015
652-2880
Hours: 8:30-5 M-F
Initial screening fee: Kaiser members 0-$5

MULTNOMAH

Dianne Heath
2525 NW Lovejoy
Portland, OR 97210
223-4959
Hours: M 9-5; T 9-12: F 9-5
Initial screening fee: $35
Can provide free screening if necessary

Denise Kossover-Wechter
St. Vincent Medical Office Bldg.
9155 SW Barnes Rd. #831
Portland, OR 97225
297-2996
Hours: 9-5, audiologist not in every day
Initial screening fee: $28
Can provide free screening if necessary

Carolyn B. Talbott
Audiology Associates
2222 NW Lovejoy #607
Portland, OR 97210
227-5109
Hours: 9-5 M T Th F
Initial Screening Fee: $30
Can provide free screening if necessary

Rodney Pelson
Don Plapinger
Child Development & Rehabilitation Center (CDRC)
Oregon Health Sciences University
Portland, OR
494-8088
Hours: 8:30-4 M-F
Initial screening fee: $60
Can provide free screening if necessary

Carolyn B. Talbott
Emanuel Hospital
2801 N. Gantenbein
Portland, OR 97227
280-4505
Hours: 9-5 W
Initial Screening fee: $28.50

Please note:

The fees listed may have changed. Contact the audiologist for the most current fee schedule.

David J. Lilly
Good Samaritan Hospital and Medical Center
1040 NW 22nd Avenue
Portland, OR 97210
229-7860
Hours: 8:30-5:30 M-F
Initial screening fee: $71
Can provide free screening if necessary

Judy Matsumoto
Carolyn Talbott
Infant Hearing Resource
3930 S.W. Macadam Avenue
Portland, OR 97201
494-4206
Hours: 8:30-5 M-F
Initial screening fee: $30

Marge Fine
Teri Hall
Kaiser Health Center West
3325 N. Interstate Ave.
Portland, OR 97227
287-2471
Hours: 8:30-5 M-F
Initial screening fee: Kaiser members 0-$5

Julie Purdy
Oregon Health Sciences University
3181 SW Sam Jackson Park Road
Portland, OR
494-8510
Hours: 8-5:30 M-F
Initial screening fee: $36

Peter Charuhas
Portland Center for Hearing & Speech
3515 SW Veteran's Hospital Road
Portland, OR 97201
228-6479
Hours: 8:30-4:30, M-F
Initial screening fee: $30-$40
Can provide free screening if necessary

Emily Maulsby
Portland State University Audiological Clinic
SW Hall and Broadway
725-3070
Hours: 9-5 M-F
Initial screening fee: $20-$40 (sliding fee scale)
Can provide free screening if necessary

Arlie Adam
Tucker-Maxon Oral School
2860 SE Holgate
Portland, OR 97202
235-6551
Hours: 8:30-3:15, M-F
Initial screening fee: $0

WASHINGTON

Marge Fine
Teri Hall
Kaiser Beaverton Medical Offices
4855 S.W. Western Avenue
Beaverton, OR 97005
643-7565
Hours: 8:30-5 M-F
Initial screening fee: Kaiser members 0-$5

CLATSOP

Jan Hankerson
Columbia Physician's Services/Surgery Clinic
2111 Exchange St.
Astoria, OR 97103
325-4321 ext. 107
Hours: 9-4:30 M-F for scheduling, 9-4:30 T-W for appointments
Initial screening fee: $20
Can provide free screening if necessary

COOS

Christopher Rainey
Coos ESD
1350 Teakwood
Coos Bay, OR 97420
269-1611
Hours: 8-4:30, M-F
Initial screening fee: $0

CURRY

Patricia A. Lashway
Pacific Coast Hearing Center
P.O. Box 4086
586 5th St. Suite 200
Brookings, OR 97415
469-3511
Hours: 9-5 M-F, Th evening upon request
Initial screening fee: $55
Can provide free screening if necessary

DESCHUTES

Cybil Koue'
Central Oregon Regional Program
520 NW Wall Street
Bend, OR 97701
385-5253
Call for information

DOUGLAS

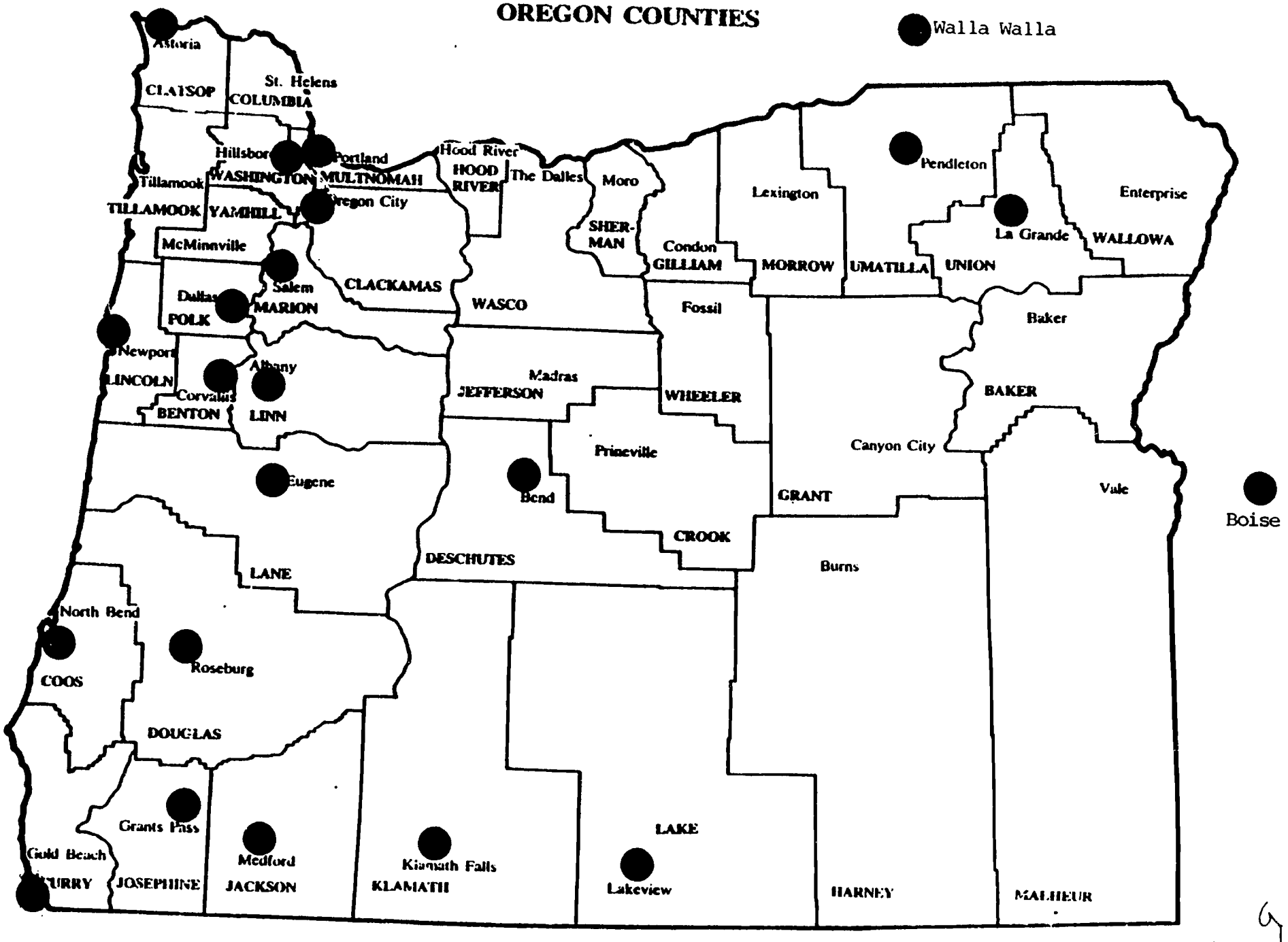
Carol Beach
Roseburg Audiology Center
1367 West Harvard
Roseburg, OR 97470
672-8868
Hours: 7:30-5:30 (closed 12:30-1:30 for lunch)
Initial screening fee: $38-$45
Can provide free screening if necessary

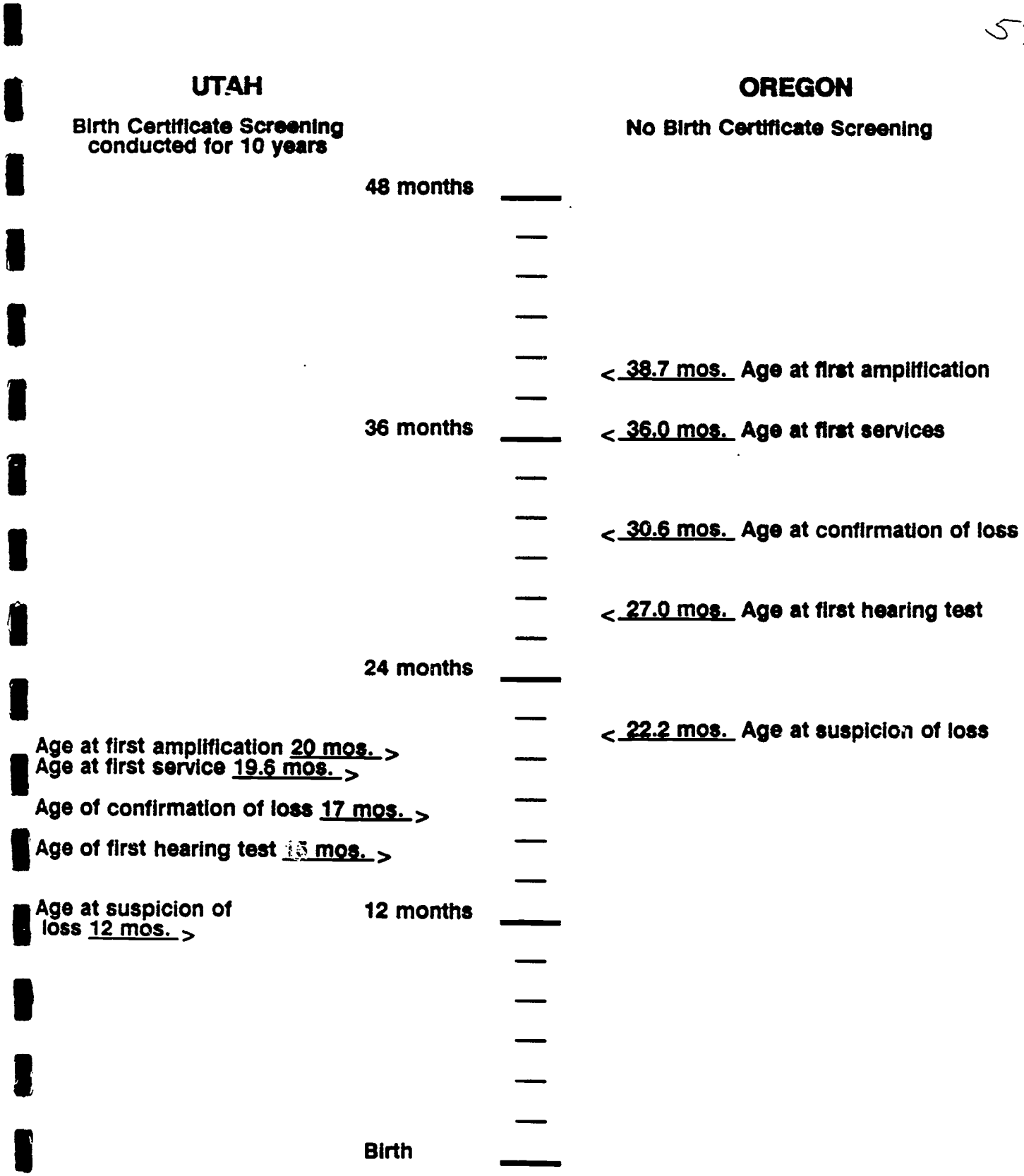
JACKSON

Wm. Strock
19 Myrtle Street
Medford, OR 97504
779-7331
Hours: 8-5 M-F
Initial screening fee: $40 approx.

Richard Croly
Jackson County ESD
101 N. Grape St.
Medford, OR 97501
776-8587
Hours: 7:30-4:30, M-F
Initial screening fee: $0 if within Jackson County--$35 if outside the county

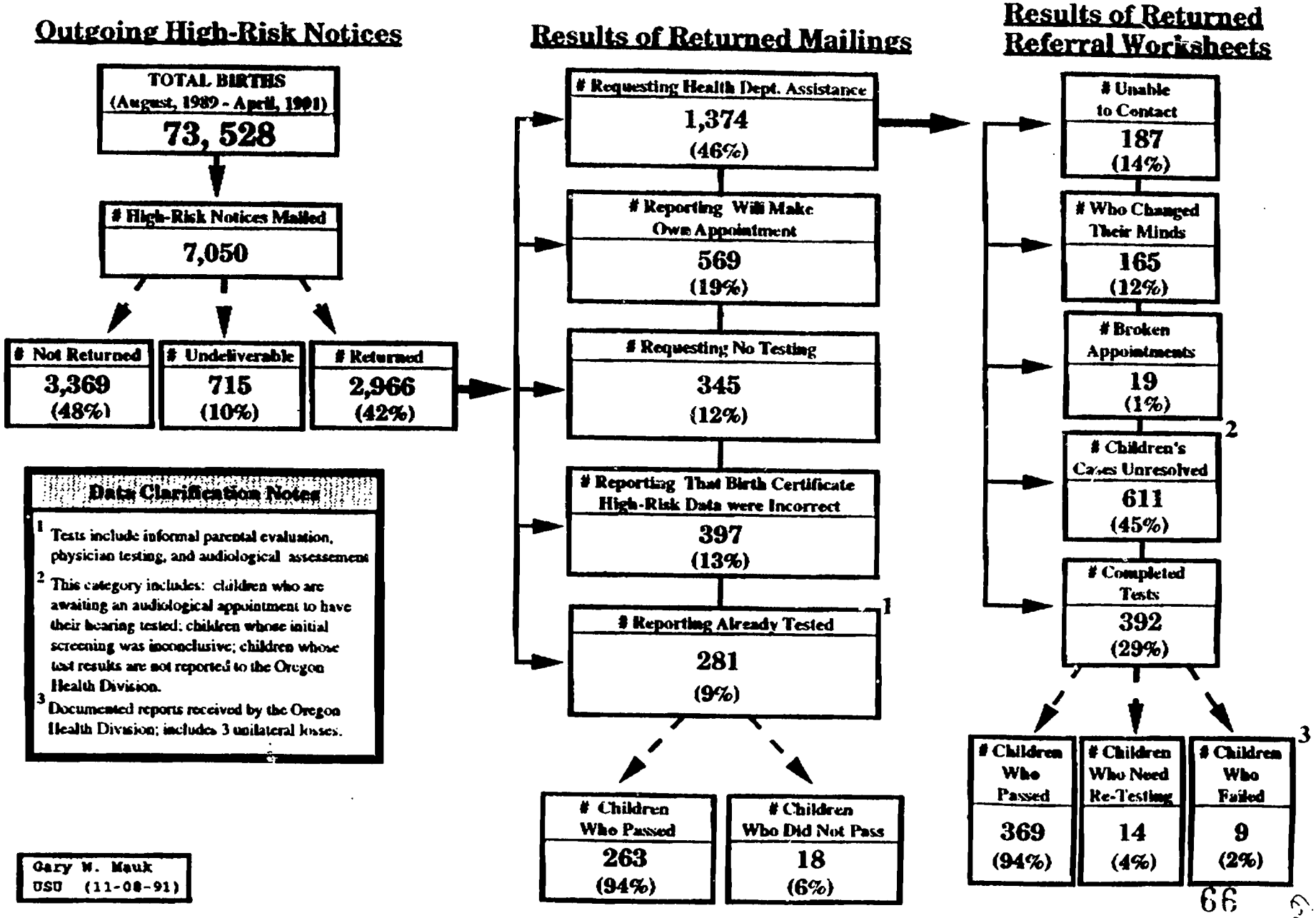
(see other side)


OREGON COUNTIES
Walla Walla
Astoria
CLATSOP
St. Helens
COLUMBIA
Hillsboro
Portland
WASHINGTON
MULTNOMAH
Hood River
HOOD RIVER
The Dalles
Moro
SHERMAN
Pendleton
Lexington
Enterprise
La Grande
WALLOWA
Tillamook
TILLAMOOK
YAMHILL
Oregon City
McMinnville
Condon
GILLIAM
MORROW
UMATILLA
UNION
Salem
CLACKAMAS
Dallas
MARION
POLK
WASCO
Fossil
Baker
Newport
LINCOLN
Albany
Madras
JEFFERSON
WHEELER
BAKER
Corvallis
BENTON
LINN
Prineville
Canyon City
Eugene
Bend
GRANT
Vale
Boise
CROOK
DESCHUTES
LANE
Burns
North Bend
Roseburg
COOS
DOUGLAS
Grants Pass
Gold Beach
Medford
Klamath Falls
LAKE
CURRY
JOSEPHINE
JACKSON
KLAMATH
Lakeview
HARNEY
MALHEUR
Indicates audiological testing site



Mean Ages at Which Children With Hearing-Impairments in Oregon and Utah Are Identified and Assisted. August, 1990

Oregon Newborn Hearing Registry Results



Data Clarification Notes

1 Tests include informal parental evaluation, physician testing, and audiological assessement

2 This category includes: children who are awaiting an audiological appointment to have their hearing tested; children whose initial screening was inconclusive; children whose test results are not reported to the Oregon Health Division.

3 Documented reports received by the Oregon Health Division; includes 3 unilateral losses.

Gary W. Mauk
USU (11-08-91)

Parents Are The First To Know If Their Infants Cannot Hear.

When you check your baby's hearing, he she should be happy and the room quiet.

DOES YOUR BABY SOMETIMES:

By Age Birth to 3 Months

- Startle or jump when there is a sudden loud sound?
- Stir or wake up and cry when someone talks or makes a noise?
- Recognize and be quieted and sometimes pacified by the sound of your voice?

By Age 3 - 6 Months

- Turn his/her eyes to look for an interesting sound?
- Respond to mother's voice?
- Turn his/her eyes toward you when you call his/her name?

By Age 6 - 12 Months

- Turn toward interesting sound and toward you when his/her name is called from behind? (Sounds need NOT be loud)
- Understand "no" and "bye-bye" and similar common words?
- Search or look around when hearing new sounds?

If your baby cannot do these things, check with your doctor.

PARENTS MUST PERSIST UNTIL THEIR CONCERNS ARE ANSWERED!

IF YOU NEED ANY HELP REGARDING YOUR INFANT'S HEARING. CALL 1-800-422-6012
OREGON HEALTH DIVISION

HOW YOUR BABY GROWS AND LEARNS

These are things most babies learn in their first year:

By about 6 weeks
- Holds head off of bed for a few moments while lying on stomach
- Follows an object with eyes for a short distance
- Pays attention to sounds
- Makes a few vocal sounds other than crying
- Looks at your face
- Smiles when you smile or play with him or her
- Moves arms and legs in an energetic manner

By about 5 months
- Holds head steady when held in a sitting position
- Laughs, squeals, and babbles
- Rolls over
- Follows with eyes from side to side
- Recognizes parents
- Brings hands together in front of body
- Reaches for and hold objects
- Passes object from one hand to other
- Begins to chew
- Stretches out arms to be picked up

By about 8 months
- Sits without support when placed in sitting position
- Takes part of weight on own legs when held steady
- Creeps (pulls body with arm and leg kicks)
- Starts to make recognizable sounds ("baa" or "daa")
- Responds to "no" and his or her name
- Grasps object off of flat surface
- Feeds crackers to self
- Looks around for a source of new sounds

By about 10 months
- Gets into sitting position on own
- Stands, holding on
- Crawls
- Picks up small object with thumb and fingers
- Tries to get an object that is out of reach
- Pulls back when you pull a toy in his or her hand
- Plays peek-a-boo
- Uses voice to get attention

By about 12 months
- Brings together two toys held in hands
- Imitates your speech
- Uses "Dada" or Mama" to mean a specific person
- Plays pat-a-cake
- Can walk holding onto something
- Finds one object under another
- Waves bye-bye
- Understands simple words and phrases ("come here")

If you are worried about how your baby moves, talks or learns, talk with your doctor or call your County Health Department and ask them about their Babies First! program.

CENSUS OF INFANTS SERVED AS HEARING IMPAIRED AS REPORTED TO THE Oregon Newborn Hearing Registry BORN*BETWEEN AUG.1989 AND NOV. 1991.

	AGE OF DIAGNOSIS (months)	ENROLLMENT	AMPLIFICATION	
Region				
VI	1	11	11	
	4	8	8	
	15	15	18	
	18	19	19	Average Diagnosis 9.5
Tucker-Maxon				
	2	2	2	
	1	1	1.25	Average Diagnosis 1.5
Infant Hearing				
	1	16	16	
	1.5	2.5	2.5	
	4.5	6	4.5	
	20	22	20	Average Diagnosis 6.75
(Regional Average: 6.8)				
V	15	15	16	
	7	9	7	
	6	7	7	
	13	13	14	
	14	14	15	
	4	4	n/a	Average Diagnosis 9.83
IV (none reported)				
Eugene Hearing and Speech				
	6	6	7	
	10	10	11	
	5	8	9	Average Diagnosis 7
III	3	5	8	
	13	14	16	
	1	6	n/a	
	3.5	15	15	Average Diagnosis 5.1
II (none reported)				
I (none reported)				

AVERAGE AGE OF DIAGNOSIS: 7.3 months (n=23)

*born in Oregon

AGE OF DIAGNOSIS AND RISK STATUS

Age in Months	n	Risk Factor(s)	No Risk Factor
1	5	CHARGE, ICU(cleft lip) FamHist, FamHist	
		FamHist	
2	1	FamHist	
3	2	Goldenhar	None (babysitter suspected)
4	3		None (sibs at CDRC)
			None (premie)
5	1	CMV	None (Kaiser peds)
6	2	FamHist, Atresia(Goldenhar)	
7	1	ICU(Atresia)	
8			
9			
10	1		None (family suspected)
11			
12			
13	2		None (parent suspected)
14	1	Meningitis	None (?)
15	2	ICU(Asst.Vent.>30)	None (parent suspected; club foot)
16			
17			
18	1	ICU(CP screen)	
19			
20	1	Atretic ear canals	

underline indicates infant in Registry computer system at Health Division

ONHR
2/92

Oregon Newborn Hearing Registry CENSUS INTERPRETATION

Q: How many of the 23 infants identified as hearing-impaired and in services had a risk factor?

A: 14 (61%)

Q: How many infants were actually in the computer at the Health Division as having a risk factor and therefore on the Registry?

A: 9

Q: How many of these 9 parents responded to the notification from the Health Division by returning the form?

A: 6
- 1-will make own appt.
- 4-already been tested
- 1-not interested

Q: If 14 infants actually had risk factors, how did the Registry miss 5?

A:
- 3 birth certificates, from 3 different hospitals, were marked NO family history when there was. (2-siblings, 1-both parents)
- 1 birth certificate showed cranio-facial anomalies, but the ICD-9 coding did not match Registry screening coding.
- 1 infant with atretic ear canals was not noted by the hospital on the birth cert.

Q: How many infants were diagnosed even before the mailing could have been sent from the Health Division?

A: 12

Q: How did the infants with no known risk factors get into testing and service?

A:
- 2 - family suspicious
- 1 - babysitter suspicious
- 1 - sibling with developmental problem, therefore family already at CDRC and looking for possible other problems.
- 1 - premie (but birth cert. was clean) (34 wks.)
- 1 - Kaiser pediatrics referred to audiology
- 1 - infant with club foot, family at CDRC already--suspected hearing problem
- 1 - ?

OHNR
2/92

Teaching Research Division

A state, regional, and national mission of research and program development.

MEMORANDUM

TO: Oregon Newborn Hearing Registry Audiologists

FROM: Jean A. Josephson and William Moore

DATE: August 6, 1992

RE: Infant hearing screening reporting

At the May 13, 1992 meeting of the Oregon Newborn Hearing Registry Advisory Committee, the decision was made to request that audiologists who serve as referral sources for the infant hearing screening program report results on EVERY BABY SCREENED. The reasons for this request are two fold.

1. There appears to be substantial underreporting of infant hearing screening to the state Health Division. By simplifying the form for reporting, and by including every baby in the program, whether risk factors are present or not, we will be able to get more accurate data on the number of babies being screened. The Health Division has the capability of scoring infants by name and birth date, and will be able to track which infants have risk factors, whose parents have been notified, and what the results of the screening are, etc.

2. With accurate counts of how many infants in the state are having their hearing screened before their first birthday, the results of the screening, and how many enter services at what age, the Health Division will be in better position to support (defend?) continuation or modification of the hearing registry program.

For a one-year period, we are asking your cooperation in completing this brief form. You may mail the form to the Health Division monthly, or when it's full, or whatever system works for your office. We will provide feedback to you on the results of this reporting.

You will need to continue to obtain parental consent to report to the Health Division. We have written a short explanation of the program and reason for reporting that you may wish to give to parents when asking for their cooperation.

Obtaining enough information to evaluate a program as diverse and as dependent on voluntary cooperation as the Oregon Newborn Hearing Registry is not a simple task. We are depending on your understanding of the importance of early identification and your commitment to improving services for families. We also know that you appreciate the need for good data to support continuation of any state funded program. Thank you for your participation.

For Women, Children and Teens

CALL 1-800-SAFENET
1-800-723-3638

OREGON HEALTH DIVISION

OREGON NEWBORN HEARING REGISTRY

Audiologist/Agency: _____ **Reporting Date:** _____

Infant Name: _____ Date of Birth: _____

Date of screen: _____

Not Abnormal_____ Referred for Medical Management_____ Sensorineural Loss_____ Needs Rescreen_____

Comment:

Infant Name: _____ Date of Birth: _____

Date of screen: _____

Not Abnormal_____ Referred for Medical Management_____ Sensorineural Loss_____ Needs Rescreen_____

Comment:

Infant Name: _____ Date of Birth: _____

Date of screen: _____

Not Abnormal_____ Referred for Medical Management_____ Sensorineural Loss_____ Needs Rescreen_____

Comment:

Return to: Oregon Newborn Hearing Registry
Child Health Coordinator Ste. 865
Oregon Health Division
800 NE Oregon Street #21

(503) 731-4399
FAX (503) 731-4083
TDD-Nonvoice (503) 731-4031

Oregon

DEPARTMENT OF
HUMAN
RESOURCES

HEALTH DIVISION

A MESSAGE TO PARENTS ABOUT HEARING SCREENING REPORTING

Babies begin learning to listen and to speak during their first year of life. To do this, they must be able to hear. As a service to families, the Oregon Health Division conducts a program to identify babies who may have a hearing loss. This program is called the Oregon Newborn Hearing Registry.

To improve our program, and to better serve other families in the state, we ask your cooperation in sharing information about your baby's hearing test with the program planners at the Health Division. All information is confidential, and will be used only by the Health Division to evaluate the effectiveness of our service.

Thank you for your part in improving this health service to Oregon's children and their families.

Sincerely,

Grant Higginson MD

Grant Higginson, M.D., M.P.H.
Medical Consultant
Center for Child and Family Health

Barbara Roberts
Governor

800 NE Oregon Str
Portland, OR
503) 731-40
503) 232-

OREGON
HEALTH
DIVISION

CONSENT FOR RELEASE OF MEDICAL INFORMATION FOR OREGON NEWBORN HEARING REGISTRY

I hereby consent to the release and disclosure of medical information:

1. Patient's name: _____

2. Patient's Date of Birth: _____

3. Audiologist releasing information: _____

4. Name of institution receiving information: | Purpose (how will information be used):

   a. Oregon State Health Division | Program planning

   b. _____ (Local Health Dept.) | Follow-up

   c. _____ (Private Provider) | Ongoing health care

   d. _____ (Other) | _____

5. What is to be released: Final result of hearing test

6. a. This consent is subject to revocation at any time, except to the extent that action has been taken in reliance upon this consent before notice of revocation.

   b. THIS CONSENT EXPIRES: 90 days from date below, or: ___/___/___ (specify date)

7. SIGNATURE: _____ DATE: _____
   (Parent or Guardian)

Audiologist: Please keep this original with your patient's records.

Oregon
STATE SYSTEM OF HIGHER EDUCATION
TEACHING RESEARCH DIVISION
345 NORTH MONMOUTH AVENUE
MONMOUTH, OREGON 97361
(503) 838-1220, EXT. 391

Dear Audiologist:

This survey is being sent to all licensed audiologists in the state of Oregon as part of the Oregon Newborn Hearing Registry Project, funded by the Office of Maternal and Child Health. The purpose of the survey is to learn what audiological resources are available throughout Oregon, particularly as they relate to the assessment of infants (birth - 2 years of age).

The Oregon Newborn Hearing Registry Project is an interagency effort of the Oregon Department of Education, Oregon Public Health Division and Teaching Research.

Your cooperation and timeliness in the completion of this survey is greatly appreciated. Please return by September 1, 1989.

Sincerely,

Wm. Moore

Wm. Moore, Project Analyst
Oregon Newborn Hearing Registry Project

OREGON SURVEY OF AUDIOLOGICAL RESOURCES

NAME: _____ Business Phone: _____

Complete WORK ADDRESS information below if it is different from address on envelope.

WORK ADDRESS: _____
Street Suite/Room # P.O. Box

_____
City State Zip Code

PRIMARY EMPLOYER (check one)

____	(1)	Private practice	____	(5)	Health care facility
____	(2)	School district (LEA, ESD, Regional Program)	____	(6)	Public agency
____	(3)	College/university	____	(7)	Industry
____	(4)	Hospital	____	(8)	Other

BM3.9

PLEASE RESPOND BY FILLING IN THE BLANK OR CIRCLING THE APPROPRIATE CHOICE:

(1) How many years of testing experience have you had with infants? (birth-2 yrs.)

____ years

(2) Approximately how many infants do you test per year?

____ infants

(3) What equipment do you have for testing infants?

_____

_____

_____

(4) At how many months of age do you feel comfortable doing behavioral assessment (VRA)?

____ months of age

(5) What are your present PASS/FAIL criteria for infants?

_____

_____

_____

(6) Do you have access to facilities for doing ABR testing of infants?

(1) YES (2) NO

a. If you perform ABR testing yourself, how many years of experience do you have?

____ years

b. If you don't perform this testing yourself, to which facility do you refer? _____

_____

(7) Depending on the evaluation demands and neec of the project, would you be interested in doing audiological assessments of infants as part of a referral system for infants who are at high-risk for hearing impairment?

(1) YES
(2) MAYBE, but I need more information
(3) NO

****

Thank you for your participation. Please return this survey in the postage-paid envelope provided by September 1, 1989.

BM3.9

NEIL GOLDSCHMIDT
GOVERNOR

Department of Human Resources
HEALTH DIVISION
1400 SW 5th AVENUE, PORTLAND, OREGON 97201

1-800
(503)442-6012
TDD-NONVOICE: (503) 229-5497

Dear Parent:

Babies begin learning to listen and to speak during their first year of life. To do this, a baby must be able to hear.

As a service to families, the Oregon Health Division uses health information on birth certificates (such as hearing loss in the family, prematurity, and/or the newborn's physical condition) to help identify babies who may have a hearing loss. These families can then get help for their babies quickly, when it does the most good.

* Can your baby hear?

Information on your baby's birth certificate suggests that your baby may have a higher chance than many babies of having a hearing loss. THIS DOES NOT MEAN THAT YOUR BABY HAS A HEARING LOSS! The occurrence of deafness is about one in 60 of these newborns, so the chance of your baby's involvement is small. We strongly suggest, however, that you have your baby's hearing tested.

* How can a baby's hearing be tested?

An audiologist, a person trained to test hearing, can do so at any age. The hearing screening takes about 30 minutes. Your baby will be awake and will probably sit on your lap during the testing.

* How much will it cost?

Hearing screening can be done with little or no charge to parents.

Please mark ONE box on the enclosed form and return it to our office in the postage-paid envelope.

For more information, call 1-800-422-6012.

Teaching Research Division

A state, regional, and national mission of research and program development.

Oregon Newborn Hearing Registry

Instructions to Medicaid Providers*

The Medicaid Program will cover the cost of an initial audiological screening for clients referred by the Oregon Newborn Hearing Registry.

All Medicaid clients who have a private physician or are part of a Physician Care Organization (PCO) may have an audiological screening without physician referral.

1. All Kaiser clients must be referred to Kaiser for screening.

2. For **clients belonging to PCOs**, the audiologist will need to write "Oregon Newborn Hearing Registry" in Box 19 of the HCFA-1500 (billing form), and send the form to the client's PCO. The PCO will put their referring number on the claim and forward it to AFS for payment.

3. For **clients not belonging to an HMO or PCO**, the audiologist will need to write "Oregon Newborn Hearing Registry " in Box 19 of the HCFA-1500. This claim should be mailed directly to AFS for payment.

4. The audiologist will send a report of the hearing screening to the primary care physician.

The Medicaid Program has agreed to allow an initial audiological screening without physician referral, but any other services will need to be referred back to the primary care physician.

*These instructions are provided by Debra J. Waln, Medical Policy Analyst, Health Program and Policy Unit, Health Services Section, Adult and Family Services Division, Public Service Building, Salem, Oregon 97310, (503) 378-5581.

January, 1990

Office: (503) 838-8391 • FAX: (503) 838-8150 • TDD (503) 838-8821
Monmouth, OR 97361

Oregon
STATE SYSTEM OF HIGHER EDUCATION
TEACHING RESEARCH DIVISION
345 NORTH MONMOUTH AVENUE
MONMOUTH, OREGON 97361
(503) 838-1220, EXT. 391

October 31, 1989

To: Newborn Hearing Registry Project Participants

From: Jean A. Josephson

Re: Hearing Screening Protocol

Please review the enclosed draft prepared by Rod Pelson and project audiologists. All licensed audiologists who agree to adhere to the protocol and criteria addressed here, and who are interested and able to participate in the project, will be included on the "recommended" list.

Rod is interested in your comments. Please call him at CDRC (503) 279-8356. Or respond to me at (503) 771-3259 and I will relay your ideas to Rod.

January fast approaches. If you have questions or comments, please react quickly. Thanks.

75

Rod Pelson
CDRC 503-279-8356

DRAFT

Newborn Hearing Registry Project
Hearing Screening Protocol

A. Required Test Protocol:

1. Test Equipment:

A. "Calibrated" sound field speaker system utilizing dual loudspeakers. (See sound field calibration procedure under "B".)

B. Visual Reinforcement Audiometry (VRA) utilizing at least a single VRA set-up.

C. All behavioral hearing screening shall be performed within a sound treated test room of sufficient size to permit placement of the loudspeakers at locations suitable for sound field VRA testing. Speaker placement should be at a 45 degree angle from client position and at a distance of 1.5 meter, plus or minus .5 meter. (See exhibit A.)

D. Tympanometry re: ASHA guidelines required to be administered only to those infants who fail the hearing screening.

2. Test Stimuli and Screening Levels:

A. Speech at 20dBnHL

AND

B. Warbled pure tones at 3000Hz or 4000Hz at 30dBnHL.

OR

C. Narrow band noise centered at 4000Hz or 6000Hz at 30dBnHL.

3. Screening Failure Criteria:

A. Inability to be conditioned to VRA.

B. Failure to demonstrate repeatable responses to speech or selected high frequency test stimuli at noted screening levels.

C. Failure to demonstrate localization to identified test stimuli at noted screening levels.

D. Failure to demonstrate normal middle ear function via tympanometry in those infants failing the hearing screening.

B. Sound Field Calibration Procedure:

There is no published standard for the calibration of sound field speaker systems. A number of methods have been suggested, however. Procedures vary from one audiometer manufacturer and installation/calibration technician to the next. Therefore, for the purposes of the Newborn Hearing Registry Project, the following behavioral "calibration" procedure is required of all audiology facilities wishing to participate in the hearing screening of identified Project children.

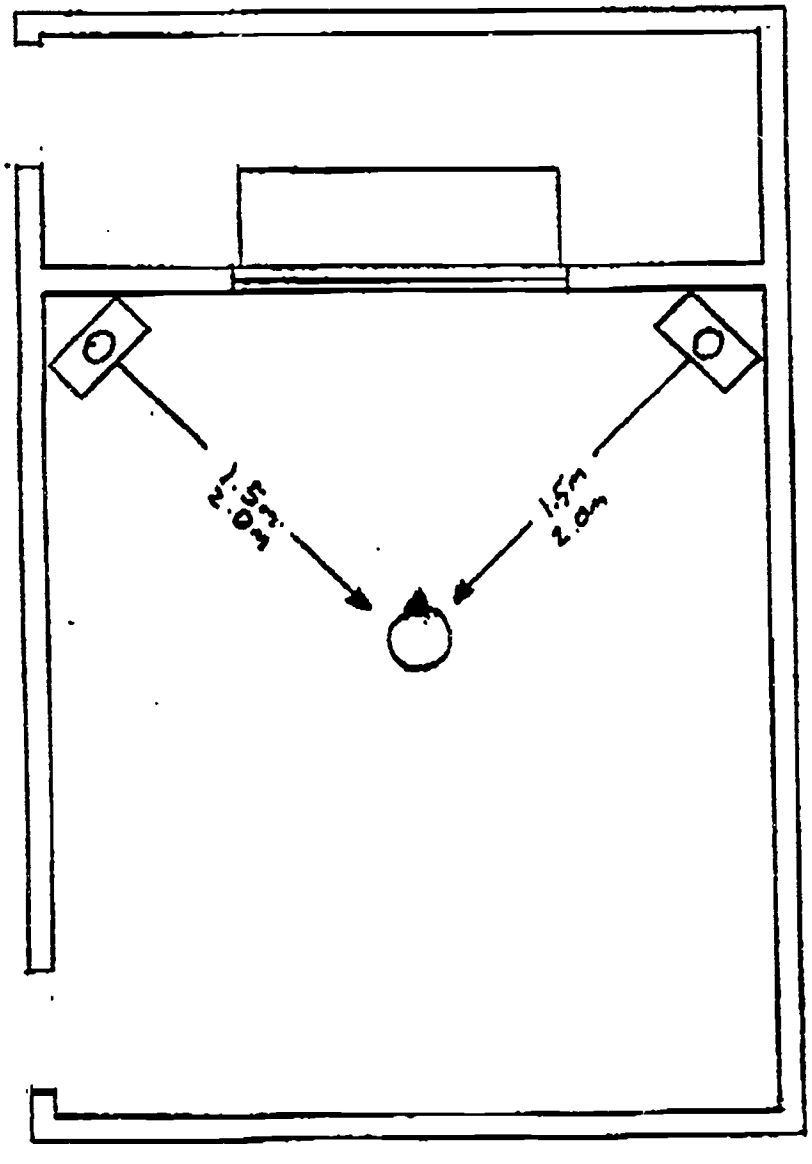
1. Identify 3-5 normal hearing older children or adults.
2. Measure and record hearing threshold levels under earphones for speech and the Project selected warbled pure tones (3000Hz or 4000Hz) or narrow bands of noise (4000Hz or 6000Hz) for each of the normal hearing subjects for both ears. Compute the mean threshold value for the subject group for speech and warbled pure tones or narrow band noise. These mean earphone threshold values for the selected stimuli become the references for the sound field testing phase of the "calibration" procedure.
3. Establish the exact position within the test room where the infants will be placed during all future project testing. This position must be equidistant from both loudspeakers.
4. For each of the "calibration" subjects, select the better ear (if there is one) and occlude the contralateral ear (earplug, ear impression material, etc.).
5. Position each subject within the test room at the exact position identified under #3 above.
6. With the subjects facing first one loudspeaker and then the other, measure and record the sound field thresholds for the selected test stimuli.
7. Compute the mean threshold values as in #2 above and compare these with those obtained under earphones. Correct for differences. For example, if the sound field speech threshold average is 10dB poorer than that obtained

for earphones, you can assume the sound field speaker output is weaker than the earphone output by this amount. Your correction factor for sound field speech threshold testing is therefore -10dB from the dial reading. If you do not wish to make an actual output change to your sound field system by an adjustment to the amplifier, then a correction chart will be helpful. In this instance were one to screen a project infant with speech at 20dBnHL, the attenuator dial would have to be set at a 30dB reading in order to make up for the lower output from the speaker system.

8. Follow the above procedure for all Project screening stimuli and for each speaker.
9. If one has access to a sound level meter, readings can be taken from the test location for each stimulus at a 70 or 80dB attenuator setting. Record these values for future reference and periodic system checks.

10/89

Exhibit A



(CHECK ONE BOX) 79

I want my baby's hearing tested at your office in Salt Lake City ☐ Ogden ☐ Vernal ☐

I would prefer M T W Th AM PM
(Circle preference. Appt. will soon be mailed to you)

OR I will have my baby's hearing tested by a licensed audiologist ☐

OR I have already had my baby's hearing tested ☐
by: NAME _____
ADDRESS _____
_____ RESULTS _____

Since I live in an outlying area, please schedule my baby for a hearing test at the next clinic in:

CEDAR CITY ☐ ST. GEORGE ☐ BLANDING ☐
MOAB ☐ RICHFIELD ☐ PRICE ☐
LOGAN ☐ PROVO ☐

OR I have no concerns about my baby's hearing and do not want a hearing test. ☐

OR Other: _____

Your Phone #: _____

DROP IN MAIL BOX - NO POSTAGE NEEDED
Please return as soon as possible

UTAH DEPARTMENT OF HEALTH
DIVISION OF FAMILY HEALTH SERVICES
44 Medical Drive
Salt Lake City, Utah 84113

NO POSTAGE NECESSARY IF MAILED IN THE UNITED STATES

BUSINESS REPLY MAIL
FIRST CLASS PERMIT NO. 6229 SALT LAKE CITY, UTAH

POSTAGE WILL BE PAID BY ADDRESSEE

UTAH DEPARTMENT OF HEALTH
DIVISION OF FAMILY HEALTH SERVICES
BUREAU OF COMMUNICATIVE DISORDERS
ATTN: High Risk Hearing Program
44 Medical Drive
Salt Lake City, Utah 84113

UTAH DEPARTMENT OF HEALTH
Bureau of Communicative Disorders

Dear Parent,

Information on your baby's birth certificate (such as hearing loss in the family, low birthweight, and/or the newborn's physical condition) suggests your baby might have a higher chance of having a hearing loss. The occurrence of deafness is about one in 200 of these newborns, so the chance of your baby's involvement is very small. However, we suggest you have your baby's hearing tested as a precautionary measure.

One of the services of the Bureau of Communicative Disorders of the Utah Department of Health is the early identification of hearing-impaired infants. As part of the services we use health information from birth certificates to help us identify infants who may have a hearing loss.

In order to have your baby's hearing tested by our office, please check the proper box on the enclosed postage-paid card and mail it to our office. The Bureau of Communicative Disorders offers hearing screening to the high risk infant without charge to parents.

For more information or additional assistance call 533-6175.

(see reverse side)

KEEP THIS CARD

HEARING LOSS CAN AND SHOULD BE DISCOVERED LONG BEFORE SCHOOL AGE

Your child's most important learning will take place between birth and four years of age. In the first four years of life, the child learns how to communicate—first to understand what people say, and then to start talking himself. To do this, your baby must have usable hearing.

The checklist below is a basic guide to normal hearing development. As time goes by, check to see if your baby can do most of the things listed. If he can't, don't wait. He may have a hearing problem.

CHECKLIST

Is startled by loud sounds.	**birth to 3 months**
Is soothed by mother's voice.	
Responds to mother's voice.	
Imitates his own noises—ochs, ba-ba's, etc.	**3 to 6 months**
Enjoys rattles and other sound-making toys.	
Turns eyes and head to search for location of sound.	
Responds to his own name, telephone ringing, and someone's voice, even when not loud.	**6 to 10 months**
Understands "no," "bye-bye," and other common words.	
Can point to or look at familiar objects or people when asked to do so.	**10 to 15 months**
Imitates simple words and sounds.	
Follows simple spoken directions.	**15 to 18 months**
First words are well on their way.	
By 18 months there should be many more words.	

For additional assistance call 533-6175

UTAH DEPARTMENT OF HEALTH
DIVISION OF FAMILY HEALTH SERVICES
BUREAU OF COMMUNICATIVE DISORDERS
44 Medical Drive
Salt Lake City, Utah 84113

(see reverse side)

8/

UTAH DEPARTMENT OF HEALTH
Bureau of Communicative Disorders

DEAR PARENT,

THIS IS A SECOND AND FINAL MAILING TO YOU. APPARENTLY YOU DID NOT RECEIVE OUR FIRST MAILING OR YOU HAVE NOT YET RESPONDED. PLEASE READ THE ENCLOSED MATERIAL CAREFULLY AND RESPOND APPROPRIATELY AS SOON AS POSSIBLE.

AS INDICATED ON THE FIRST MAILING, YOUR BABY HAS A HIGHER CHANCE OF HAVING A HEARING LOSS ACCORDING TO INFORMATION ON THE BIRTH CERTIFICATE.

FOR MORE INFORMATION OR ADDITIONAL ASSISTANCE CALL 533-6175.

UTAH DEPARTMENT OF HEALTH
Bureau of Communicative Disorders

82

SPECIAL NOTICE

Your baby was selected as being at risk for hearing loss because you indicated a family history of hearing loss on his/her birth certificate. This information, however, is often incorrect. Please review the following:

AT RISK BY FAMILY HISTORY means that a close relative's hearing loss is hereditary and that he/she has needed to wear hearing aids since childhood.

IF AFTER READING THE ABOVE YOU FEEL YOUR BABY *IS TRULY AT RISK*, return the white card requesting a hearing test.

IF AFTER READING THE ABOVE YOU FEEL YOUR BABY *IS NOT AT RISK*, return the white card and write on it, saying your baby "is not at risk".

THANK YOU

BCD-1/85

Type or print in permanent black ink. See handbook for instructions

OREGON DEPARTMENT OF HUMAN RESOURCES
HEALTH DIVISION
Vital Records Unit
CERTIFICATE OF LIVE BIRTH

Local File Number | 136- | State File Number

CHILD

1 CHILD—NAME (First, Middle, Last) | 2 SEX | 3a DATE OF BIRTH (Month, Day, Year)

3b TIME OF BIRTH | M | 4a FACILITY—NAME (If not in hospital, give street address) | 4b CITY, TOWN, OR LOCATION OF BIRTH | 4c COUNTY OF BIRTH

CERTIFIER

I certify that this child was born alive at the place and time and on the date stated above. | 5b DATE SIGNED (Month, Day, Year) | 5c CERTIFIER—NAME AND TITLE (Type or print)

5a SIGNATURE

5d NAME AND TITLE OF ATTENDANT AT BIRTH IF OTHER THAN CERTIFIER (Type or print) | 5e ATTENDANT MAILING ADDRESS (Street, city or town, state, zip)

6a DATE FILED BY REGISTRAR | 6b REGISTRAR—SIGNATURE

MOTHER

7a MOTHER—NAME (First, Middle, Last) | 7b MAIDEN SURNAME | 7c DATE OF BIRTH | 7d STATE OF BIRTH (If not in U.S.A., name country)

8a RESIDENCE—STATE | 8b COUNTY | 8c CITY, TOWN, OR LOCATION | 8d STREET AND NUMBER

8e INSIDE CITY LIMITS (Yes or no) | 8f ZIP CODE | 9 MOTHER'S MAILING ADDRESS AND ZIP CODE (If same as above, leave blank)

FATHER

10a FATHER—NAME (First, Middle, Last) | 10b DATE OF BIRTH | 10c STATE OF BIRTH (If not in U.S.A., name country)

INFORMANT

I certify that the personal information provided on this certificate is correct to the best of my knowledge and belief (Signature of Parent or other Informant)

11

ITEM CORRECTED | CORRECTED TO READ | DOCUMENTARY EVIDENCE | REVIEWED BY

INFORMATION FOR MEDICAL AND HEALTH USE ONLY

12 Shall abstract of birth certificate be made available for publication or business contact lists? (Check one) ☐ No ☐ Yes

13. Social Security Number Requested? ☐ No ☐ Yes

STATE USE ONLY a b c d

MOTHER

14a. ☐ No ☐ Yes Specify | 15a. | 16a. | 17. MOTHER MARRIED? (At birth, conception, or any time between) (Yes or no) ☐ No ☐ Yes | 18. HAS A CLOSE RELATIVE OF THIS NEWBORN HAD A HEREDITARY HEARING LOSS THAT EXISTED SINCE CHILDHOOD? ☐ No ☐ Yes

FATHER

14b. ☐ No ☐ Yes Specify | 15b. | 16b.

14. OF HISPANIC ORIGIN? (Specify No or Yes) (If yes, specify Cuban, Mexican, Puerto Rican, etc.)

15. RACE—(e.g. White, Black, American Indian, etc.) (Specify below)

16. EDUCATION (Highest grade completed) Elementary or Secondary (0-12) College (1-4 or 5+)

19. APGAR SCORE 19a. 1 min. 4 | 19b. 5 min. 7

20. BIRTH WEIGHT (Specify units) 2. 150 gr

21 PREGNANCY HISTORY

21a. LIVE BIRTHS (Do not include this child) Now living Number ____ None ☐ | 21b. Now dead Number ____ None ☐

21c. DATE OF LAST LIVE BIRTH (Month, Year)

21d OTHER TERMINATIONS (Spontaneous and induced) Number ____ None ☐

21e. DATE OF LAST OTHER TERMINATION (Month, Year)

22. CLINICAL ESTIMATE OF GESTATION (Weeks)

23. DATE LAST NORMAL MENSES BEGAN (Month, Day, Year)

24a. PLURALITY—Single, twin, triplet, etc. (Specify)

24b. IF NOT SINGLE BIRTH—Born first, second, third, etc (Specify)

25. MONTH OF PREGNANCY PRENATAL CARE BEGAN First, second, etc. (Specify)

26. PRENATAL VISITS—Total number (If none, so state)

27. SITE—PRENATAL CARE (Check all that apply) ☐ Private Clinic/Office ☐ Co. Health Dept. ☐ Other Public ☐ Other

28. PRIMARY FINANCIAL COVERAGE OF THIS DELIVERY ☐ Insurance ☐ Self pay ☐ Public Assistance ☐ Other

29. AT TIME OF THIS REPORT WAS NEWBORN ALIVE? ☐ No ☐ Yes

30. NEWBORN REQUIRED INTERMEDIATE OR INTENSIVE CARE? ☐ No ☐ Yes

31. NEWBORN TRANSFERRED FOR MEDICAL NEED? (If Yes, enter name of facility transferred to:) ☐ No ☐ Yes

32. MONTHS MOTHER ON WIC PROGRAM? (0-9)

33 MEDICAL FACTORS FOR THIS PREGNANCY (Check all that apply)

01 ☐ Anemia (Hct < 30/Hgb < 10)
02 ☐ Cardiac disease
03 ☐ Acute or chronic lung disease
04 ☐ Diabetes (Chronic)
05 ☐ Diabetes (Gestational)
06 ☐ Genital herpes
07 ☐ Hydramnios/Oligohydramnios
08 ☐ Hemoglobinopathy
09 ☐ Hypertension, chronic
10 ☐ Hypertension, pregnancy associated
11 ☐ Eclampsia
12 ☐ Incompetent cervix
13 ☐ Previous infant 4000 + grams
14 ☐ Previous preterm or small for gestational age infant
15 ☐ Renal disease
16 ☐ Rh sensitization
17 ☐ Uterine bleeding
18 ☐ No history available
00 ☐ None
19 ☐ Other (Specify) all prenatal care

34 COMPLICATIONS OF LABOR AND/OR DELIVERY (Check all that apply)

01 ☐ Febrile (>100°F or 38°C.)
02 ☐ Meconium, moderate/heavy
03 ☐ Premature rupture of membrane (>12 hours)
04 ☐ Abruptio placenta
05 ☐ Placenta Previa
06 ☐ Other excessive bleeding
07 ☐ Seizures during labor
08 ☐ Precipitous labor (<3 hours)
09 ☐ Prolonged labor (>20 hours)
10 ☐ Dysfunctional labor
11 ☐ Breech/Malpresentation
12 ☐ Cephalopelvic disproportion
13 ☐ Cord prolapse
14 ☐ Anesthetic complications
15 ☐ Fetal distress
00 ☐ None
16 ☐ Other (Specify)

35. OTHER FACTORS FOR THIS PREGNANCY (Complete all items)

a. Tobacco use during pregnancy No ☐ Yes ☐
b. Average number cigarettes per day
c. Alcohol use during pregnancy No ☐ Yes ☐
d. Average number drinks per week
e. Weight gained during pregnancy ____ lbs.
f. History available No ☐ Yes ☐
g. Other (Specify)

36. ANTENATAL PROCEDURES (Check all that apply)

01 ☐ Amniocentesis
02 ☐ Tocolysis
03 ☐ Ultrasound
04 ☐ No history available
00 ☐ None
05 ☐ Other (Specify)

37. INTRAPARTUM PROCEDURES (Check all that apply)

01 ☐ Electronic fetal monitoring
02 ☐ Induction of labor
03 ☐ Stimulation of labor
00 ☐ None
04 ☐ Other (Specify)

38 CONDITIONS OF THE NEWBORN (Check all that apply)

01 ☐ Anemia (Hct <39/Hgb <13)
02 ☐ Birth injury
03 ☐ Fetal alcohol syndrome
04 ☐ Hyaline membrane disease/RDS
05 ☐ Meconium aspiration syndrome
06 ☐ Assisted ventilation (<30 min.)
07 ☐ Assisted ventilation (>30 min.)
08 ☐ Seizures
00 ☐ None apparent
09 ☐ Other (Specify)

39 METHOD OF DELIVERY (Check all that apply)

01 ☐ Vaginal
02 ☐ Vaginal birth after previous C-section
03 ☐ Primary C-section
04 ☐ Repeat C-section
05 ☐ Forceps
06 ☐ Vacuum

40. CONGENITAL ANOMALIES OF NEWBORN (Check all that apply)

01 ☐ Anencephalus
02 ☐ Spina bifida/Meningocele
03 ☐ Hydrocephalus
04 ☐ Microcephalus
05 ☐ Other central nervous system anomalies (Specify)
06 ☐ Heart malformations
07 ☐ Other circulatory/respiratory anomalies (Specify)
08 ☐ Rectal atresia/stenosis
09 ☐ Tracheo-esophageal fistula/Esophageal atresia
10 ☐ Omphalocele/Gastroschisis
11 ☐ Other gastrointestinal anomalies (Specify)
12 ☐ Malformed genitals
13 ☐ Renal agenesis
14 ☐ Other urogenital anomalies (Specify)
15 ☐ Cleft lip/palate
16 ☐ Polydactyly/Syndactyly/Adactyly
17 ☐ Club foot
18 ☐ Diaphragmatic hernia
19 ☐ Other musculoskeletal/integumental anomalies (Specify)
20 ☐ Down Syndrome
21 ☐ Other chromosomal anomalies (Specify)
00 ☐ None apparent
22 ☐ Other (Specify)

NEIL GOLDSCHMIDT
GOVERNOR

Department of Human Resources
HEALTH DIVISION
1400 SW 5th AVENUE, PORTLAND, OREGON 97201
(503) 229-6552
TDD-NONVOICE: (503) 229-5497

February 14, 1991

TO: Medical Records Directors/Birth Certificate Clerks

FROM: Sharon Rice, Manager, Registration Unit
Center for Health Statistics

SUBJECT: CHANGE IN DEFINITION - OREGON BIRTH CERTIFICATE
 # 30 - NEWBORN REQUIRED INTERMEDIATE OR INTENSIVE CARE?

This office provides information from question number 30 on the Oregon birth certificate for tracking high risk infants and possible hearing impaired infants.

The people involved in the follow back in these two programs have asked that we not include "intermediate care" in our definition of question number 30. They found that follow back on infants receiving this level of care was not required for their programs.

We are changing the definition for question # 30 to include only the following:

> **Intensive Care: Constant nursing and continuous cardiopulmonary and other support for severely ill infant. 1/**
>
> **1/ Guidelines for Perinatal Care: American Academy of Pediatrics, American College of Obstetricians and Gynecologists**

You should implement this change immediately. Please make the necessary changes in your written procedures on "Completing the 1989 Oregon Revised Birth Certificate". (page 26)

We will change the question on the birth certificate the next time we have to reorder our supply. You should continue to use the supply of certificates you currently have on hand.

cc: County Vital Records
CHS - Statistical Unit
Hearing Program
Infant Tracking Program

30

OREGON NEWBORN HEARING REGISTRY
Medical Staff Presentations

DATE	FACILITY	CONTACT	PHONE	LOCATION
5/23/90	Providence Seaside 9 attended	Jan Hankerson, Aud.	738-8463	Seaside, OR
6/6/90	Kaiser Sunnyside 15 attended	Martha Brooks, MD Andy Kyler, Admin. Gloria Schnell, Aud.	652-2880	Portland, OR
8/7/90	Bess Kaiser 24 attended	Virginia Feldman, MD Terri Hall, Aud.	287-2471	Portland, OR
9/4/90	Willamette Falls 16 attended	Daren Emery, DD (Ped) Mary Latimer, Med. Staff Gary McClellan, Aud.	656-1631	Oregon City, OR
9/18/90	Salem Hospital 12 attended	Pat Cozad, Med. Staff Robert Goetz, MD Beverley Kay, Cont. Ed. Norman Frink, Aud.	370-5200	Salem, OR
10/18/90	Albany General 18 attended	Karen, Med. Staff Sec. Sue Peterson, Aud. Nancy Dunn, Aud.	926-2244	Albany, OR
10/25/90	OHSU 40+ attended	Berkeley Powell, MD Julie Purdy, Aud. Judy Matsumoto, Aud.	494-8392	Portland, OR
1/7/91	Valley Community 14 attended	Terri Parsons, Cont. Ed. Carol Yetter, Aud.	623-8301	Dallas, OR
1/14/91	Lebanon Community 12 attended	Jay McSpaden, Aud.	451-1631	Lebanon, OR
2/6/91	Willamette Falls 11 attended	Mary Latimer, Med. Staff Dr. Smucker (Fam. Practice)	656-1631	Oregon City, OR
3/22/91*	Providence Medical Center	Lani Miller, MD Valerie, Med. Staff	230-6023	Portland, OR
4/23/91*	Columbia Memorial	Jan Hankerson, Aud.	325-4321	Astoria, OR

*scheduled

Retrospective Survey
of
Identification of Hearing Impairment
in
Children

OREGON VERSION

Gary W. Mauk
Department of Psychology
Early Identification of Hearing Impairment Project
Utah State University
Logan, Utah

March, 1990

Column(s)

CARD # 01 1-2

CASE ID #: _____ 4-6

(1) PERSON PROVIDING INFORMATION: What is your relationship to the child? 8

(1) _____ Mother
(2) _____ Father
(3) _____ Grandparent
(4) _____ Legal Guardian
(5) _____ Foster Parent
(6) _____ Other: _____

CHILD'S HEARING HISTORY:

(2) During your child's early months of life, did your child between the ages of (MARK ALL THAT APPLY)

[a] _____ (Birth-3 months) startle or jump when there was sudden loud sound 10

[b] _____ (Birth-3 months) stir or awaken from sleep or cry when someone talked or made a noise 11

[c] _____ (Birth-3 months) recognize and was comforted by the sound of a familiar voice 12

[d] _____ (3-6 months) turn his/her eyes to look for an interesting sound 13

[e] _____ (3-6 months) respond to mother's voice 14

[f] _____ (3-6 months) turn his/her eyes forward when his/her name was called 15

[g] _____ (6-12 months) turn toward interesting sound and nor toward you when his/her name was called from behind [sound did not have to be loud] 16

[h] _____ (6-12 months) understand "No" and "Bye-Bye" and similar common words 17

[i] _____ (6-12 months) search or look around when new sounds were present 18

(3) Which of the above alerted you to a possible hearing problem? _____ 20

Column(s)

(4) **How old was your child when you first thought that he/she had a hearing problem?** 22-23

_____ Months of Age

(5) **Who suggested/recommended that you have your child's hearing tested? (MARK ALL THAT APPLY)**

(a) _____ SELF 25
(b) _____ Spouse 26
(c) _____ Relative (specify): _____ 27
(d) _____ Friend 28
(e) _____ Babysitter 29
(f) _____ Day care worker 30
(g) _____ Preschool teacher 31
(h) _____ Family physician 32
(i) _____ Nurse 33
(j) _____ OTHER: _____ 34

(6) **To whom/where did you first go for help? (MARK ONLY ONE)** 36

(a) _____ General Practitioner
(b) _____ Pediatrician
(c) _____ Audiologist
(d) _____ Community Clinic
(e) _____ ENT Specialist
(f) _____ OTHER: _____ _____

(7) **What did they do/say? (MARK ALL THAT APPLY)**

(a) _____ Tested the child 38
(b) _____ Referred the child to a specialist (e.g., audiologist, ENT physician, etc.) 39
(c) _____ Told you nothing was wrong with the child's hearing 40
(d) _____ Said something like: "Don't worry. Let's wait for a while and see if anything else shows up. If so, you can make another appointment." 41
(e) _____ OTHER: _____ 42
_____

Column(s)

(8) **Were you satisfied with their advice?** 44

(0) _____ NO

(1) _____ YES

(9) **At what age did your child have his/her first hearing test?** 46-47

_____ Months of Age

(10) **Where/by whom was it done? (MARK ONLY ONE)** 49

(a) _____ General Practitioner

(b) _____ ENT Specialist

(c) _____ Pediatrician

(d) _____ Community Clinic

(e) _____ Audiologist

(f) _____ OTHER: _____

(11) **Please describe the type(s) of test(s) that was/were performed: (MARK ALL THAT APPLY)**

(a) _____ Noisemakers [using rattles, horns, watches, snapping of fingers, etc. to which the child responds] (localizing to sound) 51

(b) _____ Behavioral Observation Audiometry (BOA) [e.g., looking for a startle response from the child] 52

(c) _____ Visual Reinforcement Audiometry (VRA)/Conditioned Orienting Response (COR) (SPEAKERS) [child is in a sound room and has to search for sounds emitted through speakers] 53

(d) _____ Visual Reinforcement Audiometry (VRA)/Conditioned Orienting Response (COR) (EARPHONES) [child is in a sound room and has to search for sounds emitted through earphones] 54

(e) _____ TROCA [child receives candy or token for response to an auditory stimulus] 55

(f) _____ Play Audiometry [child has to complete a task such as putting a peg in a board, dropping an object in a bucket, stringing beads, etc. in response to an auditory stimulus] 56

(g) _____ Traditional Audiometry [child raises his/her hand or makes other appropriate physical indication in response to an auditory stimulus] 57

(h) _____ Auditory Brainstem Response (ABR) ("The Brain Test") 58

_____ DON'T KNOW

Column(s)

(12) **Was your child diagnosed as "hearing impaired" by this test?** 60

(0) _____ NO (If "No," go to Number 13)

(1) _____ YES (If "Yes," go to Number 16)

(13) **At what age was your child first DIAGNOSED as "hearing impaired?"** 62-63

_____ Months of Age

(14) **Where/by whom was it done? (MARK ONLY ONE)** 65

(a) _____ General Practitioner

(b) _____ ENT Specialist

(c) _____ Pediatrician

(d) _____ Community Clinic

(e) _____ Audiologist

(f) _____ OTHER: _____

(15) **What type of test was performed? (MARK ALL THAT APPLY)**

(a) _____ Noisemakers [using rattles, horns, watches, snapping of fingers, etc. to which the child responds] (localizing to sound) 67

(b) _____ Behavioral Observation Audiometry (BOA) [e.g., looking for a startle response from the child] 68

(c) _____ Visual Reinforcement Audiometry (VRA)/Conditioned Orienting Response (COR) (SPEAKERS) [child is in a sound room and has to search for sounds emitted through speakers] 69

(d) _____ Visual Reinforcement Audiometry (VRA)/Conditioned Orienting Response (COR) (EARPHONES) [child is in a sound room and has to search for sounds emitted through earphones] 70

(e) _____ TROCA [child receives candy or token for response to an auditory stimulus] 71

(f) _____ Play Audiometry [child has to complete a task such as putting a peg in a board, dropping an object in a bucket, stringing beads, etc. in response to an auditory stimulus] 72

(g) _____ Traditional Audiometry [child raises his/her hand or makes other appropriate physical indication in response to an auditory stimulus] 73

(h) _____ Auditory Brainstem Response (ABR) ("The Brain Test") 74

_____ DON'T KNOW

Column(s)

CARD # 02 1-2

CASE ID #: _____ 4-6

(16) **What was your child's hearing loss as detected by the test?**

(a) RIGHT EAR		(b) LEFT EAR	
(1)	_____ NORMAL	(1)	_____ NORMAL
(2)	_____ Mild	(2)	_____ Mild
(3)	_____ Mild to Moderate	(3)	_____ Mild to Moderate
(4)	_____ Moderate	(4)	_____ Moderate
(5)	_____ Moderate to Severe	(5)	_____ Moderate to Severe
(6)	_____ Severe	(6)	_____ Severe
(7)	_____ Severe to Profound	(7)	_____ Severe to Profound
(8)	_____ Profound	(8)	_____ Profound
(9)	_____ DON'T KNOW	(9)	_____ DON'T KNOW
(10)	_____ COULD NOT DETERMINE	(10)	_____ COULD NOT DETERMINE

RIGHT 8-9

LEFT 11-12

(17) **Has your child's hearing loss become worse over time?** 14

(a) (0) _____ NO (If "No," go to Question 18).

(1) _____ YES

If "YES," what is the degree of loss now?

(b) RIGHT EAR		(c) LEFT EAR	
(1)	_____ NORMAL	(1)	_____ NORMAL
(2)	_____ Mild	(2)	_____ Mild
(3)	_____ Mild to Moderate	(3)	_____ Mild to Moderate
(4)	_____ Moderate	(4)	_____ Moderate
(5)	_____ Moderate to Severe	(5)	_____ Moderate to Severe
(6)	_____ Severe	(6)	_____ Severe
(7)	_____ Severe to Profound	(7)	_____ Severe to Profound
(8)	_____ Profound	(8)	_____ Profound
(9)	_____ DON'T KNOW	(9)	_____ DON'T KNOW
(10)	_____ COULD NOT DETERMINE	(10)	_____ COULD NOT DETERMINE

RIGHT 16-17

LEFT 19-20

Column(s)

(18) **Is your child's loss CONDUCTIVE, SENSORINEURAL, or MIXED?**

(a) RIGHT EAR	(b) LEFT EAR	
(1) _____ Conductive	(1) _____ Conductive	RIGHT 22 LEFT 24
(2) _____ Sensorineural	(2) _____ Sensorineural	
(3) _____ Mixed (conductive and sensorineural)	(3) _____ Mixed (conductive and sensorineural)	
(4) _____ DON'T KNOW	(4) _____ DON'T KNOW	
(5) _____ COULD NOT DETERMINE	(5) _____ COULD NOT DETERMINE	

(19) **How old was your child at age of first amplification?** 26-27

_____ Months of Age

(20) **How old was your child when he/she first received services (e.g., Parent-Infant Program, speech/language therapy, classification as "hearing-impaired" and serviced in a special education program, etc.)?** 29-30

_____ Months of Age

(21) **Is there a history of childhood hearing loss in the child's family?** 32

(a) (0) _____ NO (If "No," go to Question 22.)

(1) _____ YES

If "YES," please state the relationship(s) to the child and the age of occurrence/detection of the loss(es):

(b) Relationship to child: _____ 34

Age at which loss occurred/was detected: _____ 35-36

(c) Relationship to child: _____ 38

Age at which loss occurred/was detected: _____ 38-40

(d) Relationship to child: _____ 42

Age at which loss occurred/was detected: _____ 43-44

(e) Relationship to child: _____ 46

Age at which loss occurred/was detected: _____ 47-47

Column(s)

(22) **Soon after birth, was your child identified as having any of the following conditions/problems? (MARK ALL THAT APPLY)**

(a) _____ Childhood German measles (Rubella) 50

(b) _____ Toxoplasmosis 51

(c) _____ A birth defect of the head or neck (such as cleft lip and palate) 52

(d) _____ Birthweight 3 lbs. 5 oz. (1500 g.) or less 53

(e) WHAT WAS THE BIRTHWEIGHT?

_____ **pounds** ____ **ounces** [Total Ounces = _____]---->54-56

(f) _____ Severe "yellow jaundice" (highly elevated bilirubin) 57

(g) _____ Meningitis (an infection of the spinal canal and brain) 58

(h) _____ Cytomegalovirus (CMV) 59

(i) _____ Breathing difficulty (asphyxia) 60

(j) _____ Prematurity 61

(k) HOW MANY WEEKS BELOW FULL TERM (40=Full)?

_____ **weeks** 62-63

(l) _____ Mumps 64

(m) _____ Herpes 65

(n) _____ Syphilis 66

(23) **After birth, was your child in a neonatal intensive care unit (NICU)?** 68

(0) _____ NO

(1) _____ YES

Column(s)

(24) **Does your child have any other disabilities in addition to hearing loss? (MARK ALL THAT APPLY)**

(a) _____ VISUAL IMPAIRMENT 70

(b) _____ CEREBRAL PALSY 70

(c) _____ INTELLECTUAL HANDICAP 72

(d) _____ SEIZURE DISORDER 73

(e) _____ DOWN SYNDROME 74

(f) _____ LEARNING DISABILITY 75

(g) _____ OTHER: _____ 76

DEMOGRAPHIC INFORMATION

Column(s)

CARD # 03 1-2

CASE ID #: _____ 4-6

(25) **What STATE was your child born in?:**

_____ (postal abbreviation) 8-9

(26) **If your child was not born in Oregon, then when did you move to this state?**

_____/_____
Month Year

Month---> 11-12
Year---> 13-14

(27) **What is your current COUNTY of residence?:** _____ 16-17

(28) **What is your child's date of birth?:** _____/_____/_____
MO DAY YR

MO-> 19-20
DY-> 21-22
YR-> 23-24

(29) **What is your child's GENDER?:** (0) _____ MALE 26

(1) _____ FEMALE

(30) **What is the highest level of EDUCATION COMPLETED by the FATHER?:** 28
(Check the appropriate category.)

(a) _____ Non-high school graduate
(b) _____ High school graduate
(c) _____ Less than 1 year of post-high school training/college
(d) _____ 1 to 3 years of college or trade/vocational training or Associate Degree
(e) _____ Bachelor's Degree
(f) _____ Graduate Degree

Column(s)

(31) **What is the FATHER'S PRESENT OCCUPATION?** 30-31
(Check the appropriate category.)

(1) _____ Homemaker

(2) _____ Professional: Medical
(e.g., physician, dentist, pharmacist, nurse, health technician)

(3) _____ Professional: Non-medical
(e.g., computer specialist, engineer, lawyer, scientist, librarian, clergyman, counselor)

(4) _____ Professional - Education
(public-private/university)

(5) _____ Manager/Administrator

(6) _____ Sales

(7) _____ Clerical

(8) _____ Laborer/Craftsman

(9) _____ Farmer

(10) _____ Transportation Worker
(e.g., bus or truck driver, delivery person, railroad worker)

(11) _____ Service Worker
(cleaning, food, health, personal, and protective services)

(12) _____ Other: _____

(32) **What is the highest level of EDUCATION COMPLETED by the MOTHER?:** 33
(Check the appropriate category.)

(a) _____ Non-high school graduate

(b) _____ High school graduate

(c) _____ Less than 1 year of post-high school training/college

(d) _____ 1 to 3 years of college or trade/vocational training or Associate Degree

(e) _____ Bachelor's degree

(f) _____ Graduate Degree

Column(s)

(33) **What is the MOTHER'S PRESENT OCCUPATION?** 35-36
(Check the appropriate category.)

(1) _____ Homemaker

(2) _____ Professional: Medical
(e.g., physician, dentist, pharmacist, nurse, health technician)

(3) _____ Professional: Non-medical
(e.g., computer specialist, engineer, lawyer, scientist, librarian, clergyman, counselor)

(4) _____ Professional - Education
(public-private and university)

(5) _____ Manager/Administrator

(6) _____ Sales

(7) _____ Clerical

(8) _____ Laborer/Craftsman

(9) _____ Farmer

(10) _____ Transportation Worker
(e.g., bus or truck driver, delivery person, railroad worker)

(11) _____ Service Worker
(cleaning, food, health, personal, and protective services)

(12) _____ Other: _____

(34) **What is the ETHNIC ORIGIN of your CHILD?** 38

(1) _____ Caucasian

(2) _____ Hispanic

(3) _____ Native American

(4) _____ Black

(5) _____ Asian

(6) _____ Pacific Islander

(7) _____ OTHER: _____

++

Column(s)

(35) SOCIOECONOMIC STATUS INFORMATION (optional): 40

When I mention the category into which your family's annual income falls, please say "YES":
(Check the appropriate category.)

(a) _____ UNDER $5,000
(b) _____ $5,000 - $10,000
(c) _____ $10,000 - $20,000
(d) _____ $20,000 - $30,000
(e) _____ $30,000 - $40,000
(f) _____ $40,000 - $50,000
(g) _____ OVER $50,000

^ ^ ^ ^ ^ ^ ^ ^ ^ ^ ^ ^ ^ ^ ^

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD?

_____

_____

_____

_____

_____

THANK YOU! WE APPRECIATE THE INFORMATION YOU HAVE PROVIDED.

Interviewer's Signature: _____

Date of Interview: ____/____/____
MO DAY YR

Month--> 42-43
Day--> 44-45
Year--> 46-47

Maternal Data

33-34 ___ ___ Number of prenatal visits
35-36 ___ ___ Gravidity
37-38 ___ ___ Parity
39-40 ___ ___ # of Spontaneous Abortions
41-42 ___ ___ # of Therapeutic Abortions
43-44 ___ ___ # of Living Children
45 ___ Placenta Previa
46 ___ Abruption
47 ___ Toxemia
48 ___ Preclampsia
49 ___ Hypertension
50 ___ Dependent Diabetes
51 ___ Gestational Diabetes
52 ___ Rh Incompatibility
53 ___ Substance Abuse During Pregnancy
54 ___ Unspecified
55 ___ Barbiturates
56 ___ Amphetamines
57 ___ Cannabinoid
58 ___ Cocaine
59 ___ Opiates
60 ___ Phencyclidine
61 ___ Other_____
62 ___ Substance Abuse at Delivery
63 ___ Unspecified
64 ___ Barbiturates
65 ___ Amphetamines
66 ___ Cannabiniod
67 ___ Cocaine
68 ___ Opiates
69 ___ Phencyclidine
70 ___ Other_____
71 ___ Maternal HIV
72 ___ Herpes
73 ___ Type of Delivery

Neonatal Data

1 2 Record #
2-8 _____ Child ID#
9-14 _____ Date of Birth
15-18 _____ Birth Weight
19-20 _____ Gestational Age
21 ___ 1-minute Apgar
22 ___ 5-minute Apgar
23 ___ Severe Asphyxia
24 ___ Meningitis
Congenital Infections
25 ___ Cytomegalovirus
26 ___ Rubella
27 ___ Herpes
28 ___ Toxoplasmosis
29 ___ Syphilis
Malformation of Head/Neck
30 ___ Dysmorphic
31 ___ Pinnae
32 ___ Cleft Palate
33-35 ___ ___ ___ Hyperbilirubinemia
36 ___ Tx for Hyperbilirubinemia
37 ___ Size for Gestational Age
38 ___ Respiratory Distress Syndrome
39 ___ Broncho-Pulmonary Dysplasia
40 ___ Pneumonia
41-43 ___ ___ ___ # of Days of O_2
44 ___ Recurrent Apnea
45-47 ___ ___ ___ # of Days of Intubation
48 ___ Patent Ductus Arteriosus
49 ___ Other Congenital Heart Defect
50 ___ Left IVH
51 ___ Right IVH
52 ___ Progressive Ventricular Dilatation
53 ___ Seizures
54 ___ Retinopathy of Prematurity
55 ___ Antibiotics
56-58 ___ ___ ___ Days in Normal Care Nursery
59-61 ___ ___ ___ Days in NICU
62 ___ Gender

OAE Screen Results

100

Record# [1: 3] Child ID# [2 3 4 5 6 7 8]

Cols.	RIGHT EAR		Cols.	LEFT EAR	
9-11	Peak	Noise Level	35-37	Peak	Noise Level
12-14	#Low		38-40	#Low	
15-17	#High		41-43	#High	
18-20	Echo	Response	44-46	Echo	Response
21-23	Repro.		47-49	Repro.	
24-26	Peak	Stimulus	50-52	Peak	Stimulus
27-29	Stab.		53-55	Stab.	
30-31	Probe ID		56-57	Probe ID	
32-33	Tester ID		58-59	Tester ID	
34	Result		60	Result	

ABR Screen Results

Cols.			Cols.		
1	4	Record #	40-42	Latency 3	RIGHT EAR, 60 dB # 1
2-8		Child ID#	43-45	Latency 5	
9-11	Latency 3	RIGHT EAR, 30 dB # 1	46	RESULT	
12-14	Latency 5		47-49	Latency 3	RIGHT EAR, 60 dB # 2
15	RESULT		50-52	Latency 5	
16-18	Latency 3	RIGHT EAR, 30 dB # 2	53	RESULT	
19-21	Latency 5		54-56	Latency 3	LEFT EAR, 60 dB # 1
22	RESULT		57-59	Latency 5	
23-25	Latency 3	LEFT EAR, 30 dB # 1	60	RESULT	
26-28	Latency 5		61-63	Latency 3	LEFT EAR, 60 dB # 2
29	RESULT		64-66	Latency 5	
30-32	Latency 3	LEFT EAR, 30 dB # 2	67	RESULT	
33-35	Latency 5		68-69	Tester ID	
36	RESULT		70	Machine ID	
37-38	Tester ID				
39	Machine ID				

Cols.		
1	5	Record #
2-8		Child ID#
9-11	Latency 3	RIGHT EAR, 90 dB # 1
12-14	Latency 5	
15	RESULT	
16-18	Latency 3	RIGHT EAR, 90 dB # 2
19-21	Latency 5	
22	RESULT	
23-25	Latency 3	LEFT EAR, 90 dB # 1
26-28	Latency 5	
29	RESULT	
30-32	Latency 3	LEFT EAR, 90 dB # 2
33-35	Latency 5	
36	RESULT	
37-38	Tester ID	
39	Machine ID	

Name: _____ Revised 4/23/90 101

1 - 8

RHODE ISLAND HEARING ASSESSMENT PROJECT

CONGRATULATIONS ON THE BIRTH OF YOUR BABY! To help us provide you with better services, we would appreciate you taking a few minutes to provide us with some information about yourself and your baby.

For each item below, PLEASE WRITE THE APPROPRIATE NUMBER IN THE BOX TO THE LEFT OF THE ITEM.

9 ☐ Do any of your baby's relatives have a permanent hearing loss?

0 = NO 1 = YES

10-11 ☐ Your Age (years)

12 ☐ What is the PRIMARY language spoken in your home?

13 ☐ Is there a SECONDARY language spoken in your home? (if not, write "0" in the box)

1 = English
2 = Portuguese
3 = Spanish
4 = Cambodian
5 = Laotian
6 = Vietnamese
7 = Hmong
8 = OTHER: _____ (specify)

14 ☐ Your Marital Status

1 = Single 4 = Divorced
2 = Married 5 = Widowed
3 = Separated 6 = Live together

15 ☐ Your Education

16 ☐ Education of Baby's Father

1 = Less than 7th grade
2 = 9th grade
3 = 10th - 11th grade
4 = High school graduate
5 = Partial college
6 = College graduate
7 = Graduate school

17 Your Occupation: _____

18 Baby's Father's Occupation: _____

19-20

21-22

23-24

Thank You For Your Help!

EOAE, ABR, and Behavioral Evaluation Data Code Explanations

DATA CODE	Initial Test		Re-Screen		Sedated ABR	Behavioral Audiometry	Hearing Sensitivity
	OAE	ABR	OAE	ABR			
0	Too Old	Too Old	Too Old	Too Old			SENSORINEURAL
1	Pass	Pass	Pass	Pass	Normal Hearing	Normal Hearing	Normal < 20 dB
2	Partial Pass	Fail @ 30 dB	Partial Pass	Fail @ 30 dB	Conductive: Fluct.	Conductive: Fluct.	Fail > 20 < 30 dB
3	Fail	Fail @ 60 dB	Fail	Fail @ 60 dB	Conductive: Perm.	Conductive: Perm.	Fail > 30 < 60 dB
4		Fail @ 90 dB		Fail @ 90 dB	Sensorineural Loss	Sensorineural Loss	Fail > 60 < 90 dB
5	Invalid-Retest	Invalid-Retest	Invalid-Retest	Invalid-Retest	Mixed Loss	Mixed Loss	Fail > 90 dB
6			Lost Child	Lost Child	Lost Child	Lost Child	
7	Could Not Test	Could Not Test	Could Not Test	Could Not Test	Could Not Test	Could Not Test	
8	Did Not Test	Did Not Test	Did Not Test	Did Not Test	Did Not Test	Did Not Test	
9	MISSING DATA	MISSING DATA	MISSING DATA	MISSING DATA	MISSING DATA	MISSING DATA	
A			Not Referred for Re-Screen	Not Referred for Re-Screen			FLUCTUATING CONDUCTIVE Fail > 20 < 30 dB
B			Broke Appt.	Broke Appt.	Broke Appt.	Broke Appt.	Fail > 30 < 60 dB
C	Parent Refused	Parent Refused	Parent Refused	Parent Refused	Parent Refused	Parent Refused	Fail > 60 < 90 dB
D			Deceased	Deceased	Deceased	Deceased	Fail > 90 dB
E			Scheduled	Scheduled	Scheduled	Scheduled	
F			Referred Ped.	Referred Ped.	Referred Ped.	Referred Ped.	
G			Discharged by Audiologist	Discharged by Audiologist	Tested Elsewhere: No Results Yet	Tested Elsewhere: No Results Yet	
H			No Rescreen: Med. Reasons	No Rescreen: Med. Reasons	Referred for Behavioral Aud.		
I	NOT USED	NOT USED	NOT USED	NOT USED	NOT USED	NOT USED	NOT USED
J						Referred For Sedated ABR	PERMANENT CONDUCTIVE Fail > 20 < 30 dB
K							Fail > 30 < 60 dB
L							Fail > 60 < 90 dB
M							Fail > 90 dB
N						More testing indicated; Parents refused	

Clarification of Data Code Explanations

DATA CODE	EXPLANATION	CLARIFICATION
0	Too Old	During the initial stages of the project, re-screen procedures were not yet operational. Because re-screens are most successful with children less than eight weeks of age, some children became too old for re-screens to be conducted, and were consequently referred for behavioral audiometry.
5	Invalid-Retest	Test did not fall within the established parameters for a valid test.
6	Lost Child	Parent could not be contacted (e.g., phone disconnected, moved with no forwarding address). Sometimes referred to as "could not locate."
7	Could Not Test	Test could not be administered because of time constraints, state of child, equipment failure, etc.
8	Did Not Test	Tester chose not to conduct the test even though the test should have been administered.
9	MISSING DATA	
A	Not Referred for Re-Screen	Prior to 9/1/90, if, on the initial screening, a child had a "fail" or a "partial pass" on the OAE but "passed" the ABR, the child was not scheduled for a re-screen.
F	Referred to Pediatrician	After repeated attempts to schedule the child for a re screen or after repeated cancellations/broken appointments by the parent/guardian, a referral was made to the child's pediatrician for follow up.
G	Tested Elsewhere: No Results Yet	Parent(s) report(s) that their child has been tested elsewhere (e.g., by an ENT) and results of the testing have not yet been received by the RIHAP.
H	Referred for Behavioral Aud.	Child has been referred to RISD for behavioral audiometry.
J	Referred for Sedated ABR	Child has been referred to Rhode Island Hospital for sedated ABR evaluation.
N	More Testing Indicated; Parents Refused	Behavioral observation audiometry results indicated the need for further testing, but the parents refused to follow through on the recommendation for further testing.

Appendix B

Professional Publications/Presentations

The Effectiveness of Screening Programs Based on High-Risk Characteristics in Early Identification of Hearing Impairment

Gary W. Mauk, MA, CAGS; Karl R. White, PhD; Lance B. Mortensen, BA; Thomas R. Behrens, PhD

Utah State University, Logan, Utah (G.W.M., K.R.W., L.B.M.) and United States Department of Education, Washington, DC (T.R.B.)

ABSTRACT

Prompt identification of educationally significant hearing loss is yet an unattained goal. However, there is some evidence that the ability to identify and diagnose hearing loss at an early age has been significantly improved through the use of carefully designed screening protocols such as birth certificate-based high-risk registries. To evaluate the efficiency of birth certificate-based screening programs, 70 parents and guardians of 6- to 9-yr-old children with significant sensorineural losses were surveyed regarding their child's identification history. Each of these children was born in the state during the time a birth certificate-based screening program was in full operation. Results indicate that children with at least one risk factor for hearing impairment were identified an average of 7.7 mo earlier than children with no risk history. However, only 50% of the children with sensorineural hearing losses exhibited any of the risk factors and a significant number of children with risk factors were missed by the system. Had admission to a neonatal intensive care unit been considered a risk factor, 63% of the children would have exhibited at least one risk factor. More extensive implementation of high-risk registries in conjunction with more widespread education of parents and primary care providers regarding early behavioral indicators of hearing loss, procedures for referral, and appropriate intervention and management services needs to be considered (Ear Hear 12 5:312–319).

HEARING LOSS IN infants is one of the most common disabilities in the United States (Madell, 1988). One child per 1000 is born deaf (Cox, Hack, & Metz, 1984; Das, 1988; Stein, Ozdamar, Kraus & Paton, 1983b); an additional 2 children per 1000 are deafened during childhood (Coplan, 1987). An equal number suffer from permanent, partial hearing loss of disabling proportions (Bergstrom, Hemenway, & Downs, 1971; Downs, 1986; Simmons, 1978, 1980). According to the 12th Annual Report to Congress on the Implementation of the Education of the Handicapped Act, approximately 11 in every 10,000 children require special education services as a result of hearing impairments (U.S. Department of Education, 1990).

Because the ability to hear during the first 3 yr of life is critical for the acquisition of spoken language, prelingual hearing impairment carries with it two disabilities: hearing loss and language delay (Allen & Schubert-Sudia, 1990; Lenneberg, 1967; Skinner, 1978; Yoshinaga-Itano, 1987). Failure to identify hearing loss and provide intervention (amplification, speech therapy, and/or sign language instruction) before this period has a needless negative effect on language development beyond the effect of the hearing loss itself (Downs, 1986; Kretschmer & Kretschmer, 1978; McFarland & Simmons, 1978; Ross, 1990). The importance of earlier intervention is underscored by the fact that hearing-impaired children who receive intervention before 2.5 years of age have significantly better communicative skills than children who receive similar intervention at later ages (Clark, 1979). Such improved communication skills are basic to future psychosocial, educational, and vocational development (Elliot & Armbrusher, 1967; Levitt & McGarr, 1988; Madell, 1988; Schlesinger & Meadow, 1972; Schum, 1987).

Unfortunately, the average delay between birth and the detection of sensorineural hearing loss is 2.5 yr (Academy of Otolaryngology-Head and Neck Surgery, 1990; Pappas & Mundy, 1981). For the 1 to 2 children in 1000 born with a sensorineural hearing loss, this delay may unfortunately extend well into the critical early years of language and speech development (Morgan, 1987). The developmental and psychosocial impact of such a delay in the identification of hearing loss can be devastating.

In recognition of the problems caused by delayed identification, the Joint Committee on Infant Hearing (1982) recommended that hearing loss be identified by the age of 3 to 6 mo. Recently, the federal government established a goal to "reduce the average age at which

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children with significant hearing impairment are identified to no more than 12 months" by the year 2000 (U.S. Department of Health and Human Services, 1990, p. 460).

To meet the need for early identification of hearing impairment, neonatal screening programs are being examined and, in some cases, established by state health departments, private hospitals, and audiologists. The implementation of newborn hearing screening programs has increased significantly over the past decade (Jacobson & Jacobson, 1990). Fourteen states have passed enabling legislation mandating newborn hearing screening, and several of these states are operating successful screening programs (Blake & Hall, 1990). Another 12 states, while having no legislative mandate, are currently addressing the issue by some method at the state level.

The use of the high-risk registers using the variables recommended by the Joint Committee on Infant Hearing (1982) is one method of identifying sensorineural hearing loss at an early age. One of the longest used and apparently successful methods of collecting information about the presence of these risk factors is to incorporate the relevant information into the legally required birth certificate, as has been done in Utah since 1978 (Mahoney & Eichwald, 1986, 1987). This system uses a birth certificate protocol to gather information about the following seven high-risk factors identified by the Joint Committee on Infant Hearing (1982): (1) A family history of childhood hearing impairment; (2) Congenital perinatal infection (e.g., cytomegalovirus, rubella, herpes, toxoplasmosis, syphilis); (3) Anatomical malformations involving the head or neck (e.g., dysmorphic appearance including syndromal and nonsyndromal abnormalities, overt or submucous cleft palate, morphologic abnormalities of the pinna); (4) Birth weight less than 1500 g; (5) Hyperbilirubinemia at level exceeding indications for exchange transfusion; (6) Bacterial meningitis, especially *Haemophilus influenzae*; (7) Severe asphyxia (often measured with Apgar scores between 0 and 3 or infants who fail to institute spontaneous respiration by 10 min and those with hypotonia persisting to 2 hr of age).

The success of any screening system for hearing impairment depends on the degree to which the following three conditions are met: (1) Children with sensorineural hearing loss exhibit the risk factors; (2) Children with risk factors can be located for additional diagnostic testing; and (3) Appropriate follow-up services can be provided after initial suspicion and/or confirmation of a hearing loss. Unfortunately, even though the risk factors recommended by the Joint Committee on Infant Hearing have been widely advocated for over 15 years, very little empirical evidence is available about how well the three preceding conditions are met.

One of the problems with determining the efficiency of screening systems designed to identify sensorineural hearing loss is that the presence of the hearing loss for some children is often not confirmed until 3 to 5 yr later. Thus, it is difficult to know how successful the system is unless the system has been in place for an extended period of time. Because the system used in Utah has been in place since 1978 and records have been maintained, there was a unique opportunity to analyze how successful the system had been in identifying sensorineural hearing loss. The purpose of this study was to use archival information from the birth certificate-based screening program together with information about the child's hearing loss and parents' responses to a survey to determine how effective such a screening program is and what factors are associated with earlier or later identification and habilitation of sensorineural hearing loss.

METHOD

The present study undertook to discover the patterns of identification of 6- to 9-yr-old children with educationally significant, sensorineural hearing losses who were attending programs operated by the Utah School for the Deaf and who were born in Utah during the time that the birth certificate-based registry was in full operation. A listing of all children with educationally significant sensorineural hearing losses (n = 93) was obtained from the Utah School for the Deaf. Of the 93 parents/guardians on the interview list, 15 declined participation (16%), five had moved out of state before the survey and could not be located (5%), and three were parents of visually impaired students who were erroneously listed on the hearing-impaired registry (4%). Thus, 78% (70 of the 90 children with hearing impairments) of the accessible population of parents/guardians of hearing-impaired, 6- to 9-yr-old children was interviewed.

Data were collected from parents/guardians of the children using a standardized phone interview protocol. In addition to questions about general demographic characteristics, the survey protocol contained questions pertaining to the suspicion, identification, and habilitation process that the parents had experienced as well as to the children's births and medical histories. Questions were posed in the following areas: (1) neonatal risk status for hearing loss; (2) auditory-related behaviors observed (or not observed) by parents/guardians during their child's early months of life; (3) actions of the professionals whom parents first contacted because of concern for their child's hearing; (4) age of suspicion of hearing loss; (5) age of confirmation of hearing loss; (6) age of amplification; and (7) age of habilitation. Birth certificate information regarding neonatal risk factors on the total population was provided by the Utah Department of Health, Bureau of Communicative Disorders.

Telephone calls were made by trained paraprofessionals following a structured protocol that had been pilot tested and revised based on interviews with a group of 10 parents not included in the sample of 6- to 9-yr-old children. A sample of calls made was supervised by the first author to ensure consistency with the protocol. Multiple phone calls at different times of day were made to obtain responses from as many parents as possible. All interviews occurred during a 4-week period.

RESULTS

As can be seen in Table 1, only half of the sample of children exhibited any of the risk criteria recommended

Table 1. Potential detection rate of the current Joint Committee on Infant Hearing high-risk register for hearing loss.

Risk Status	*n*	Percent
High-risk	35	50
Not high-risk	35	50

by the Joint Committee on Infant Hearing (1982). These data support the findings of Elssmann, Matkin, and Sabo (1987), who reported that 48% of children with sensorineural hearing losses exhibited high-risk characteristics, and Stein, Clark, & Kraus (1983a), who stated that 25 to 30% of hearing-impaired children do not exhibit such high-risk characteristics. The most frequently demonstrated Joint Committee risk factor in the present study was family history of hearing loss (29%).

In the present study, 57% of the parents reported that their child was in a neonatal intensive care unit (NICU) immediately after birth (this figure is substantially higher than the 33% figure reported by Elssmann et al, 1987). If admittance to a NICU had been included as a risk factor with this sample, then 9 of the 35 children (26%) who were missed by the other risk factors would have been included. Including NICU admission as a risk factor would mean that 63% of children with sensorineural hearing losses in the sample would have been identified as high risk.

Another relevant issue is that of appropriate and aggressive follow-up of children who exhibit risk factors predictive of hearing impairment. In this sample of parents of high-risk children who actually had sensorineural hearing losses, only 33% of the parents requested an appointment for a hearing evaluation when they were contacted by the State's Bureau of Communicative Disorders. Most of the parents did not respond to the mailer or reported having no concerns about their children's hearing (22%), could not be located in the records of the Bureau of Communicative Disorders (19%), or responded that their child had been already tested audiologically (26%). Even among those parents who requested testing, only about one-third actually followed through and arrived for the appointment (Mahoney & Eichwald, 1986).

Table 2 lists, by degree of hearing loss of the child, the percentage of parents who noticed auditory behavior deficits in their children at three age ranges. As would be expected, the greater the degree of hearing loss and the older the age of the child, the more parents noticed that their children were not exhibiting developmentally appropriate, auditory-related behaviors. In this study, about 40% of the parents of children with moderate to profound hearing losses noticed behavioral indicators of hearing loss between birth and 3 mo of age and continued to observe them. However, many parents (21–36%) of children with mild-moderate hearing losses (25–55 dB HL) began to notice when the child was relatively young (6–12 mo of age) that their child was not responding to environmental sounds nor comprehending words which were common for the child's age.

Table 3 illustrates the importance of parental awareness of behaviors related to hearing loss. For parents

Table 2. Severity of hearing loss and developmental auditory behavior deficits observed by parents.

Auditory Behavior Deficit	Expected Age Range (in mo)	Percentage of Parents By Degree of Hearing Loss[a]
Did not startle or jump when there was a sudden loud sound	Birth–3	0—Mild-Moderate 41—Moderate-Severe (*n* = 11) 40—Profound (*n* = 11)
Did not stir or awaken from sleep or cry when someone talked or made a noise	Birth–3	7—Mild-Moderate (*n* = 1) 37—Moderate-Severe (*n* = 10) 40—Profound (*n* = 11)
Did not recognize and was not comforted by a familiar voice	Birth–3	7—Mild-Moderate (*n* = 1) 19—Moderate-Severe (*n* = 5) 31—Profound (*n* = 9)
Did not turn eyes to look for an interesting sound	3–6	14—Mild-Moderate (*n* = 2) 44—Moderate-Severe (*n* = 12) 45—Profound (*n* = 13)
Did not respond to mother's or caregiver's voice	3–6	7—Mild-Moderate (*n* = 1) 41—Moderate-Severe (*n* = 11) 35—Profound (*n* = 10)
Did not turn eyes forward when name was called	3–6	21—Mild-Moderate (*n* = 3) 44—Moderate-Severe (*n* = 12) 45—Profound (*n* = 13)
Did not turn toward interesting sound or toward caregiver when name was called from behind	6–12	29—Mild-Moderate (*n* = 4) 67—Moderate-Severe (*n* = 18) 48—Profound (*n* = 14)
Did not understand "No" and "Bye Bye" and similar common words	6–12	21—Mild-Moderate (*n* = 3) 52—Moderate-Severe (*n* = 14) 45—Profound (*n* = 13)
Did not search or look around when new sounds were present	6–12	36—Mild-Moderate (*n* = 5) 59—Moderate-Severe (*n* = 16) 35—Profound (*n* = 10)

[a] *Total n mild-moderate = 14; total n moderate-severe = 27; total n profound = 29.*

Table 3. Auditory deficit behaviors noticed first by parents and mean age of suspicion of hearing loss.

Number/Percent of Parents	Age Range of Auditory Behaviors Noticed First	Mean Age of Suspicion (mo)
24/34%	Birth–3 mo	5.5
9/13%	3–6 mo	9.8
11/16%	6–12 mo	13.7
26/37%	No behavior noticed first	18.9

who first noticed that their children were not demonstrating normal auditory awareness between birth and 3 mo of age, the mean age of suspicion was 5.5 mo; for parents who did not first suspect that their child had a hearing problem until between 6 and 12 mo of age, the mean age of suspicion more than doubled, to an average of 13.7 mo. Even more disturbing is the fact that for parents who did not first notice any auditory behavior-related deviation in their children, the mean age of suspicion was approximately 19 mo.

Table 4 shows a comparison of the identification histories of children who exhibit high-risk characteristics and those who do not, from the average age at which parents first suspected that their child had a hearing loss until the average age at which the child first entered habilitative services (e.g., parent-infant program, speech/language therapy). These results indicate that parents of high-risk children, on average, suspect a problem approximately 5 mo earlier, obtain a hearing test approximately 7 mo earlier, have their child's hearing loss confirmed approximately 8 mo earlier and have their child fitted with amplification devices and enrolled in habilitative services approximately 5 mo earlier than parents of children with no risk factors for hearing loss.

Table 5 illustrates the effects of placation and referral by primary care providers on the mean age of suspicion and confirmation of hearing loss. On average, children benefited immensely from appropriate referral by primary care providers, whether or not they exhibited high-risk characteristics. Whereas the average delay from suspicion until confirmation of hearing loss for high-risk children who were referred was 1.7 mo, the average delay for the placated group was 8.3 mo. Likewise, the average delay for lower risk children who were referred by primary care providers was 4.9 mo, whereas the delay for the placated group was 8.2 mo.

The results of an analysis of the effects of the degree of hearing loss on age of confirmation are presented in Table 6. These results suggest that children born with profound hearing losses had their losses confirmed, on average, between 8 mo (high risk) and 18 mo (not high risk) of age, as compared with 12 mo (high risk) and 17 mo (not high risk) of age for those with moderate to severe losses. Average ages of confirmation for children with mild to moderate losses ranged from 19 mo (high risk) to 38 mo (not high risk). These data are a confir-

Table 4. Comparison of high-risk and not high-risk children from mean age of suspicion of hearing loss until mean age of services.

Historical Identification Events	Utah Department of Health and Retrospective Survey Data[a] (Mean Age in mo)
High-risk[b]	(n = 35)
Age of suspicion of hearing loss	9.9
Age of first hearing test	11.3
Age of confirmation of hearing loss	12.8
Age of first amplification	17.1
Age of first services	18.2
Not high-risk[c]	(n = 35)
Age of suspicion of hearing loss	14.8
Age of first hearing test	18.7
Age of confirmation of hearing loss	20.5
Age of first amplification	22.6
Age of first services	23.1

[a] *A total of 70 children with Utah Department of Health risk data and parent survey reports of risk (Utah births only).*

[b] *Child was reported to have at least one Joint Committee risk factor for hearing impairment.*

[c] *Child was reported to have no Joint Committee risk factor for hearing impairment.*

Table 6. Degree of hearing loss, risk status and mean age at confirmation of hearing loss.

Degree of Hearing Loss	Mean Age at Confirmation (mo)		n
Mid to moderate (25–55 dB HL)	High-risk	19.2	10
	Not high-risk	38.5	4
Moderate to severe (56–90 dB HL)	High-risk	12.3	11
	Not high-risk	17.8	16
Profound (>90 dB HL)	High-risk	8.7	14
	Not high-risk	18.5	15
All losses	High-risk	12.8	35
	Not high-risk	20.5	35

Table 5. Effects of referral (good advice) and placation (poor advice) by primary care providers on mean age of suspicion and mean age of confirmation of hearing loss.

Category	Mean Age of Suspicion of Hearing Loss (mo)	Mean Age of Confirmation of Hearing Loss (mo)	Average Delay from Suspicion to Confirmation of Hearing Loss (mo)
High-risk			
Referred (n = 28)	9.7 (S.D. = 11.2)	11.4 (S.D. = 11.2)	1.7 (S.D. = 2.8)
Placated (n = 7)	10.4 (S.D. = 8.1)	18.7 (S.D. = 16.4)	8.3 (S.D. = 11.8)
Not high-risk			
Referred (n = 27)	16.3 (S.D. = 13.1)	21.2 (S.D. = 13.1)	4.9 (S.D. = 6.4)
Placated (n = 8)	9.8 (S.D. = 11.5)	18.0 (S.D. = 9.8)	8.2 (S.D. = 7.4)

mation of the inverse relationship between age of confirmation and degree of hearing loss reported previously (Elssmann et al., 1987; Malkin, Freeman, & Hastings, 1976; Shah, Chandler, & Dale, 1978).

DISCUSSION

Neonatal Risk Status and Hearing Loss

The results of this study confirm that properly implemented birth certificate-based high-risk registers are a feasible and effective means of identifying children with educationally significant, sensorineural hearing impairment at an early age. Based on the factors recommended by the Joint Committee on Infant Hearing (1982), half of the children with educationally significant sensorineural losses in the present study would be identified by such a system. Regarding the issue of relevant risk criteria for sensorineural hearing loss, previous studies have reported that the incidence of hearing loss among NICU graduates might be as high as 7% (Galambos, Hicks, & Wilson, 1982; Schulman-Galambos & Galambos, 1979; Stein et al, 1983b). In the present study, 57% of the parents reported that their child was in a NICU immediately after birth (figure is substantially higher than the 33% figure reported by Elssmann et al, 1987). If admittance to a NICU had been included as a risk actor with this sample, then 9 of the 35 children (26%) who were missed by the other risk factors would have been included, raising percentage of at-risk children with sensorineural hearing losses in the sample from 50 to 63%. Because data about admission to a NICU are much easier to collect than data about many of the other risk factors, it seems wise to add this variable as a high-risk factor for hearing impairment.

However, it is clear from this study that based on current knowledge, the use of a high-risk registry is not enough. It is important to emphasize that even though the systematic identification and screening of children exhibiting high-risk factors would result in many children with sensorineural hearing losses being identified earlier, almost 40% of hearing-impaired children do not exhibit any of these risk factors and many of the children who do exhibit high-risk characteristics do not come in for further diagnostic testing. These findings suggest the need for continued attention to regular hearing screenings up to and including the first years of formal education. Furthermore, even the best high-risk screening registry must be operated in conjunction with alert and well-education parents and physicians if hearing impairment is to be identified as early as it should be (Elssmann et al, 1987; Jacobson & Jacobson, 1990).

Supporting the need for ongoing hearing screening for all children is the fact that the most frequently demonstrated Joint Committee risk factor in the present study was family history of hearing loss (29%). However, as many as one-third of congenitally deaf infants are the result of autosomal recessive inheritance appearing in families who explicitly deny knowledge of a family history (Frasier, 1971, 1976). These children have no associated handicaps, are not ill, and are not found in special care nurseries (Morgan, 1987; Stein et al, 1983b). They are healthy, normal appearing infants. Thus, ongoing screening for all children is essential, if children with sensorineural hearing losses are to be identified as early as possible.

Of course, because of reporting errors, nonresponsive parents, and missed audiological testing appointments, it is unrealistic to expect all children with risk factors to be identified. In fact, the results from the study suggest that substantial numbers of such children would be missed. The fact that a significant number of children who exhibit high-risk characteristics are lost to the system supports the case for more aggressive administrative follow-up. For the category of parents who either did not respond to the high-risk mailing or who reported no concerns about their children's hearing, the case is supported for better education about risk factors and hearing loss for parents and primary care physicians. Furthermore, these data suggest that even if more parents who request audiological evaluations arrived for appointments, and both parents and primary care physicians are better educated about risk factors and hearing loss, record-keeping errors can still prevent many at-risk children from entering the identification and management system.

Parents' Suspicions of Hearing Loss

Many professionals acknowledge that parents are the first to suspect that their infants cannot hear (Bergstrom et al, 1971; Boison, 1987; Ling & Ling, 1978; Northern & Downs, 1984; Parving, 1984; Shah et al, 1978). Retrospective studies of parents' experiences with identification of their children's hearing losses have shown that, in more than half of the cases, the parents are the first to suspect the hearing impairment and are those who initiate the identification of the hearing thresholds (Kankkunen, 1982; Hitchings & Haggard, 1983; Hovind & Parving, 1987; Parving, 1984). Usually these suspicions are based on the child's failure to respond to certain sounds, erratic responses to sound, delayed speech development, or sometimes all of these (Garrity & Mengle, 1983; Hitchings & Haggard, 1983; Hovind & Parving, 1987).

Consistent with previous research (Hovind and Parving, 1987), the present study found that although the majority of parents notice behavioral indictors of hearing loss (e.g., the child did not startle or jump when there was a sudden loud sound between the ages of birth and 3 mo), a substantial proportion of parents (37%) do not realize that these behaviors are a warning signal of possible hearing loss. These findings suggest (1) that parents are in an ideal position to assist with the early identification of hearing impairment, but a better job of educating them about what developmentally linked behaviors are associated with hearing loss needs to be done, and (2) that many parents are

aware of the behavioral indicators of hearing loss, but do not necessarily understand their relation to hearing loss. Improved information on the perceptual development of children should be given to all parents, hopefully resulting in an optimal utilization of the signs and signals from the hearing-impaired infant. Such information could be given as an easily understandable pamphlet including a list of questions by means of which the parents can note their observations of the different stages of development. In practice, the pamphlet could be given to all mothers upon leaving the hospital after delivery and could also inform them about high-risk criteria (Hovind & Parving, 1987).

The Role of Primary Care Physicians

Previous research has reported that parents who are able to bring developmental deviations, such as suspicion of hearing loss, to the attention of appropriate professionals, such as primary care providers (e.g., pediatricians, general practitioners), are often ignored or placated (Boison, 1987; Coplan, 1987; Elssmann et al, 1987; Pappas & Mundy, 1981; Parving, 1984; Ross, 1990; Shah et al, 1978). Selected studies have reported delays of 7.1 mo (Elssmann et al, 1987), 11.5 mo (Shah et al, 1978), and 24 mo (Boison, 1987) between parental suspicion of hearing loss and physician referral for audiological assessment. Parving (1984) found that health service personnel were responsible for the delay in identification of hearing loss in approximately 60% of the cases. Astoundingly, Coplan (1987) reported delays in diagnosis of hearing impairment ranging from 24 to 48 mo; half of these children had associated physical anomalies, such as atresia of the ear canal and syndromal manifestations, that should have been clues to the presence of hearing loss.

Another issue regarding the role of primary care providers in the early identification of hearing loss relates to the inappropriate use and interpretation of the results of hearing screening tests. Although office screening for hearing loss is a laudable goal, screening children with a chronological or developmental age below 36 mo is difficult, because children at this age usually do not tolerate the placement of headphones. Therefore, the primary care provider often resorts to presented informal auditory stimuli (e.g., handclap, bell, etc.) in a sound field. Unfortunately, it is well known that the visually alert deaf child will often cue in on the physician's hand or body movements rather than the auditory stimuli being presented (Coplan, 1987).

Such a phenomenon appears to have occurred with some of the children in this study. Eight children who had confirmed hearing losses ranging from moderate to severe, six of whom were considered at risk for hearing loss, passed their first hearing test, administered by their primary care provider using noisemakers in isolation Although the average age of the this first hearing test was 12.5 mo, the average age of confirmation of their hearing loss was 17.3 mo, almost a 5 mo delay. Because primary care providers occupy such a pivotal position in the early identification of hearing loss in children, it is important that there be ongoing efforts to provide substantial education as to how to identify a hearing-impaired child (Calvert, 1986; Coplan, 1987). However, convincing busy physicians of the need to spend the time and effort necessary to become educated, do the screening, and make the referrals is an important, but daunting, task. In addition, information about the methodological insufficiency of behavioral hearing screening procedures and information about high-risk criteria should be given to all personnel dealing with infants and children (Hovind & Parving, 1987).

Even though many parents notice the indicators of hearing loss, a substantial number who accurately suspect that their child has a hearing loss are placated by primary care providers, thereby inordinately delaying diagnosis by as much as 8 mo. Additionally, primary care providers frequently administer inappropriate tests of hearing (e.g., noisemakers) in isolation, effectively passing children who later failed a more appropriate hearing evaluation. Because primary care providers occupy a pivotal position regarding early identification of developmental problems, they must be educated to screen for early signs of hearing loss and refer children appropriately for audiologic follow-up.

CONCLUSIONS

The purposes of screening of infants for hearing loss are (1) to identify, as early as possible, those children with permanent hearing losses who otherwise would not have been identified, and (2) to initiate habilitation at a time when maximum benefit for the child will occur (Roeser & Northern, 1988). Indeed, some have argued that the ultimate test of the effectiveness of a neonatal hearing screening program is the age at which hearing-impaired children are identified and the age habilitation begins (Blake & Hall, 1990). The findings of this study contrast with those of Elssmann et al (1987), who reported minimal differences between the ages at which parents of infants with no known risk factors and parents of infants at risk for hearing loss first suspected and obtained confirmation of their children's hearing losses. The fact that parents of high-risk children in this sample achieved all of the milestones from suspicion to receipt of services much earlier than parents of children who did not exhibit risk factors is evidence that a high-risk registry can be of substantial assistance in the early identification of hearing loss. Even though a substantial number of children with sensorineural hearing losses will be missed by such high-risk registries, these findings emphasize the importance of using the high-risk factors as an aid in identifying hearing loss as early as possible.

The successful implementation of screening programs to identify children with sensorineural hearing losses requires knowledge about the risk factors associated with hearing loss, design of screening programs

which are feasible to implement and capable of identifying children who have those risk factors, and successful and appropriate follow-up of children exhibiting risk factors (Jacobson & Jacobson, 1990). Despite advances in early identification of hearing loss, without adequate follow-up services, hearing screening programs such as birth certificate-based registries will continue to fall short of the objective of identifying all significant hearing losses before 12 mo of age. To provide the intervention and management strategies necessary to enable children with significant sensorineural losses to make optimal developmental progress, a combination of strategies is needed, including effective screening based on high-risk criteria, parent involvement, appropriate diagnostic testing, and education of health care professionals. Attention to such strategies would substantially reduce the average age at which children in the United States with significant sensorineural hearing losses are identified.

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Acknowledgments: Preparation of the manuscript was supported in part by project #MCJ-495037 from the Maternal and Child Health program (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services. We are very appreciative of the information and support provided by Dr. Thomas Mahoney and Mr. John Eichwald of the Utah Department of Health, Bureau of Communicative Disorders. We are also grateful to Ms. Kirsten Hammar, who assisted in the preparation of the manuscript, and Mr. Andrew Ugan, who facilitated the data transfer and coding.

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Received March 5, 1991; accepted June 14, 1991.

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Chapter 15

Neonatal Hearing Screening Using Evoked Otoacoustic Emissions: The Rhode Island Hearing Assessment Project

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INTRODUCTION

Although everyone agrees that early identification of hearing loss is important, currently available procedures in the United States have not been successful in identifying the majority of hearing-impaired children during the first year of life. This chapter describes the procedures and preliminary results of the Rhode Island Hearing Assessment Project (RIHAP), which was designed to evaluate the use of evoked otoacoustic emissions (EOAE) to screen all live births for hearing loss.

The average delay between birth and the confirmation of significant sensorineural hearing loss in the United States is 2½ years or more (Academy of Otolaryngology-Head and Neck Surgery 1990; Commission on Education of the Deaf 1988; Pappas and Mundy 1981). For children born with significant sensorineural hearing loss, this delay may unfortunately extend well into the critical early years of language and speech development. The developmental and psychosocial impact of delayed identification of hearing loss is often devastating because the ability to hear during the first 3 years of life is critical for the acquisition of spoken language.

Failure to identify hearing loss and provide intervention (amplification, parent management, speech and language management,

and/or sign language instruction) within the first year of life has needless negative effects on other areas besides language because adequate communication skills are basic to future psychosocial, educational, and vocational development (Bebout 1989; Downs 1986; Madell 1988; Sacks 1989; Schum 1987; Ross 1990). Fortunately, if hearing loss is identified early, many of the negative effects of hearing impairment can be ameliorated or eliminated. For example, Clark (1979) demonstrated that hearing-impaired children who receive intervention before 2½ years of age have significantly better communicative skills than children who receive similar intervention at later ages.

The importance of identifying hearing-impaired children at an earlier age is also underscored by the government's recently issued plan to improve significantly the nation's health over the coming decade (*Healthy People 2000: National Health Promotion and Disease Prevention Objectives*, U.S. Department of Health and Human Services 1990). One goal of that plan is to "reduce the average age at which children with significant hearing impairment are identified to no more than 12 months." The document goes on to state:

> The future of a child born with a significant hearing impairment depends to a very large degree on early identification (i.e., audiological diagnosis before 12 months of age) 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. When early identification and intervention occurs, hearing-impaired children make dramatic progress, are more successful in school, and become more productive members of society. The earlier intervention and habilitation begins, the more dramatic the benefits. (P. 460)

How likely are we to accomplish the goal of earlier identification if present policies and procedures are continued? At first glance, it appears that substantial progress is being made. A recent article by Blake and Hall (1990) noted that 14 states now have a legislative mandate to do neonatal hearing screening and 12 additional states have a policy or

program in place, even though no legislative mandate exists. Unfortunately, the current status is not as positive as these numbers suggest. Six of the 14 states have not actually implemented screening programs because no funds have been appropriated. Of the 12 states that have a policy or a program but no legislative mandate, most have only a policy that acknowledges the importance of early identification. Of the programs in existence, all limit screening to a small number of high-risk babies. Unfortunately, recent research (Elssmann, Matkin, and Sabo 1987; Mauk, White, Mortensen, and Behrens 1991) has demonstrated that at least half of all children with sensorineural hearing loss never exhibit any of these high-risk characteristics.

ALTERNATIVE METHODS FOR EARLY HEARING SCREENING

Although there is a great deal of interest in identifying children earlier, most currently used screening procedures are either too expensive to implement or miss such large numbers of children that it is unlikely that such techniques would lead to reduction of the average age of identification to 12 months of age, even if they were used by every state. The most frequently used methods available for early identification of hearing loss include the following.

BEHAVIORAL TESTING BY HOME VISITORS

Where it is feasible to make home visits to most children in the population, e.g., a country such as England with socialized medicine, this technique is very effective (Barr 1980; Bentzen and Jensen 1981; McCormick 1983). A trained home visitor uses simple behavioral testing techniques to observe whether the child responds to various noises such as rattles or bells, which are presented so that the child's hearing instead of visual responsiveness is tested. In countries where universal home visits are done, behavioral testing for hearing is very economical. In countries without universal home visiting, such as the United States, the costs would be prohibitive.

HIGH-RISK REGISTRIES

In 1982, the Joint Committee on Infant Hearing identified seven risk factors associated with hearing impairment in young children (family history of deafness, congenital infections, anatomic malformations of the head or neck, birth weight less than 1500 g, hyperbilirubinemia, bacterial

meningitis, and severe asphyxia). More recently, the 1982 criteria have been updated and expanded (Joint Committee on Infant Hearing 1991). By focusing screening only on children who exhibit one or more of these risk factors, the costs of screening are minimized. Such screening programs have been implemented where information about the risk factors is collected from the legally required birth certificate (Mahoney and Eichwald 1986; 1987) or as a questionnaire, which is completed by the mother or the hospital staff (Epstein and Reilly 1989; Schuyler and Rushmer 1987). Although children who exhibit one of these risk factors are more likely to be hearing impaired, most hearing-impaired children never exhibit any of these risk factors (Elssmann et al. 1987; Mauk et al. 1991). More widespread implementation of screening programs for children with such risk factors would certainly reduce the average age of identification. However, it is unrealistic to expect that the goal of reducing the average age of identification to 12 months of age can be accomplished by such programs since so many hearing-impaired children do not exhibit any of these risk factors.

CRIB-O-GRAM

A hospital-based alternative (Miller and Simmons 1984) uses a cradlelike device that is sensitive to movements of the baby and that can emit sound at predetermined levels and times. By monitoring whether movements of the baby correspond to the times that sound was emitted, it was hoped that early detection of hearing impairment could be possible. Unfortunately, data on the validity of such techniques have been disappointing (Shimizu et al. 1985).

AUDITORY BRAINSTEM RESPONSE (ABR)

Numerous researchers (e.g., Galambos and Despland 1980; Kileny 1988; Levi, Tell, Feinmesser, Gafni, and Sohmer 1983; Murray, Javel, and Watson 1985) have demonstrated that ABR testing is useful in identifying hearing impairment in very young children. Generally, an initial test is done a few days before the child is released from the hospital, and those who fail are rescreened several weeks later to correct for the high false positive rate of the initial screen. A very high percentage of those who fail both tests will have significant hearing impairment. The technique is accurate, but the expense and the substantial training and experience necessary for operators mean that

traditional ABR testing is not feasible as a mass hearing screen (American Speech-Language-Hearing Association 1989). Recently introduced portable ABR equipment and equipment that includes automated scoring routines may bring the costs down, but further research is necessary (Jacobson, Jacobson, and Spahr 1990; Kileny 1988). Some hospitals have also used ABR screening only for children who exhibit high-risk characteristics, but even that is more expensive than desired and has the added disadvantage of missing those hearing-impaired babies who do not exhibit any of the risk variables.

PURPOSE

The problems noted above with each of the most widely used screening techniques for early identification of hearing loss have probably contributed to the lack of success in substantially reducing the average age at which hearing-impaired children are identified. The purpose of the Rhode Island Hearing Assessment Project (RIHAP) was to determine whether evoked otoacoustic emissions (EOAEs) could be used with every live birth to reduce the average age of identification for significant hearing impairment. In other words, is a neonatal hearing screening program using EOAE feasible, valid, and cost-efficient?

FEASIBILITY

The evaluation of feasibility was based on whether it was possible to organize the logistical and procedural details of conducting a large-scale screening program in a busy hospital, and whether appropriate staff could be hired, trained, and appropriately supervised to test that many babies. Data regarding feasibility were collected by screening over 3,000 babies in regular and special care nurseries.

VALIDITY

It is also important to know whether EOAE-based screening correctly identifies children who have hearing losses, and correctly passes most children who do not have hearing losses. To determine the validity of the EOAE procedure: (*a*) data were collected for a subsample of infants with both EOAE and ABR; (*b*) the number of children with hearing losses identified with EOAE is being documented; (*c*) information is being collected about how many of those children would not have been identified using other techniques; and (*d*) information about hearing

status at 5 years of age for all children screened will be collected and referenced to the initial screening results. The follow-up data are possible because of the unusual degree of cooperation between the Departments of Education and Health in Rhode Island, and because the Rhode Island School for the Deaf is already conducting a very comprehensive screening program for all kindergarten-age children in the state. Thus, it will be possible to cross-reference all of the children who were originally screened with EOAE to their results 5 years later in kindergarten.

COST-EFFICIENCY

A screening program may be feasible and produce valid results but may be too expensive. The cost-efficiency of an EOAE screening program can be determined by analyzing whether the costs of implementing the program are reasonable, given available resources and in light of the benefits associated with early identification. The cost of screening each baby will be calculated using an ingredients approach (Levin 1983), and the cost of identifying each hearing-impaired child will be calculated by dividing the total cost of the program by the number of children identified.

PROCEDURE

Before describing the procedures used in screening infants, it is important to provide a brief explanation of what evoked otoacoustic emissions are and how they are measured. This will be followed by a summary of how the project was designed and the procedures used to collect data.

EVOKED OTOACOUSTIC EMISSIONS

Evoked otoacoustic emissions (EOAEs) are acoustic responses associated with the normal hearing process. EOAEs are produced in the inner ear by physiologic activity of the cochlea (outer hair cells) and can be measured with a low-noise microphone placed in the ear canal (Kemp 1978). EOAEs can be evoked by various stimuli in virtually all normally hearing individuals. Substantial evidence now shows that EOAEs are a property of the healthy, normal-functioning cochlea, generated by active, frequency-selective, nonlinear elements within the cochlear partition. These elements enhance the cochlear response to sound by a positive

feedback mechanism, thus improving sensitivity and frequency selectivity. Substantial recent research has shown that EOAEs are not present in adults or children with hearing loss greater than 30 dB HL (Bray and Kemp 1987; Kemp, Bray, Alexander, and Brown 1986; Probst, Lonsbury-Martin, Martin, and Coats 1987; Rutten 1980).

The physical mechanisms of the middle ear and cochlea serve to collect and concentrate sound energy onto the sensory hair cells. Vibrations generated inside the cochlea are magnified by the middle ear and transmitted into the air as sound. By placing a receiver-microphone probe into the ear canal, sounds made by the cochlea can be evoked by external sound and recorded from virtually any ear with normal mid-frequency hearing (Kemp 1989). Consequently, several researchers have suggested that EOAEs may be a valuable noninvasive, objective tool for evaluating cochlear status in infants and young children (Bonfils, Uziel, and Pujol 1988; Elberling, Parbo, Johnsen, and Bagi 1985; Johnsen, Bagi, and Elberling 1983; Kemp 1988; Lutman, Mason, Sheppard, and Gibbin 1989; Stevens et al. 1991).

The ease with which EOAEs can be measured led to the development of a commercially available device that is appropriate for screening infants (Kemp 1988). The Otodynamic Analyzer (ILO88) works by placing a probe in the ear of the child to be evaluated (see figure 1). A series of clicks is then sent into the ear canal, delayed EOAEs are recorded in the ear canal following the click stimuli, and responses are analyzed by the ILO88.

The ILO88 produces information like that in figure 2, which shows the results for a normal hearing neonate. The information in the upper

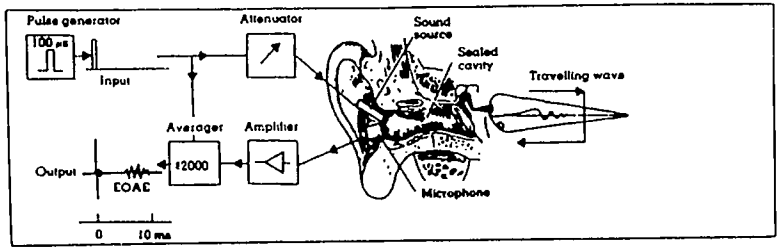

Figure 1. Basic method of recording evoked otoacoustic emissions (EOAEs) stimulated by transient sound. Reproduced from Kemp, D.T. 1989, with permission.

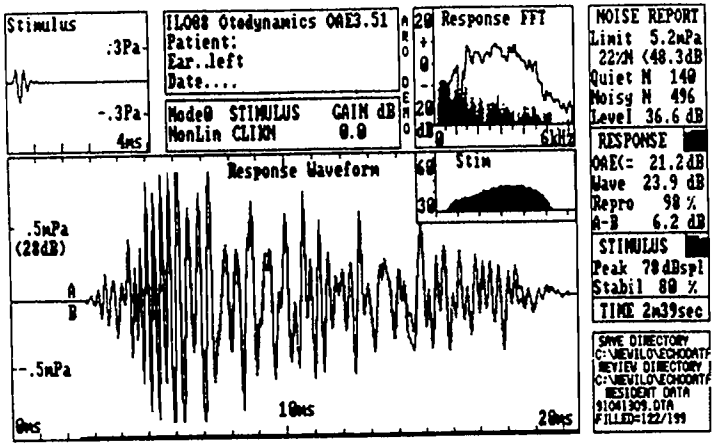

Figure 2. Example of evoked otoacoustic emissions (EOAE) from a neonate with normal hearing.

right-hand corner that shows the clear wave above the dark wave indicates that the child has hearing across the frequency range from 1 to 5 kHz. In contrast, figure 3 shows the response of a neonate who failed the screening test as indicated by the information in the upper right-hand corner where there is no waveform evident above the dark wave.

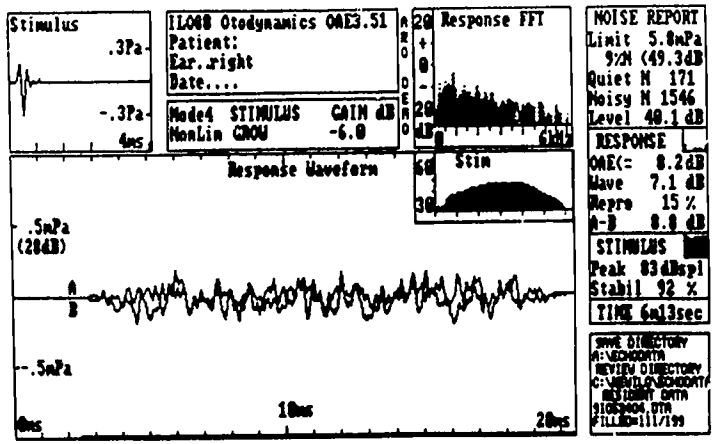

Figure 3. Example of evoked otoacoustic emissions (EOAE) from a neonate with impaired hearing.

Based on previous research with small samples, the use of EOAE in a neonatal hearing screening program has the following apparent advantages:

1. Simple. No advanced technical training is required for administration.
2. Fast. Detection of EOAEs can be achieved in less than 15 minutes for both ears.
3. Noninvasive. The acoustic probe is placed into the external ear canal using an impedance probe protector without support.
4. Objective. A visual record of cochlear response is provided for future reference.
5. Sensitive. The method is sensitive to small hearing losses (25 dB HL) over a 2 to 3 octave range.

However, EOAEs have not been used in the United States in a large-scale screening program to determine whether such an application is feasible, produces valid results, and is cost-efficient. The Rhode Island Hearing Assessment Project provides the basis for such an evaluation.

DESIGN

The RIHAP design and timelines for assessments are shown in figure 4. As can be seen, children included in the screening can be divided into two groups. Some children receive both EOAE and ABR regardless of their results on either test. If they fail either or both, they are referred for rescreening at 4 to 6 weeks. In the second group, children are first screened initially with the EOAE. If they fail the EOAE, they are tested with ABR. Whether or not they pass the ABR, they are referred for rescreening at 4 to 6 weeks.

All children who are rescreened at 4 to 6 weeks receive both EOAE and ABR. Although a number of variables influence the decision of whether to refer for further testing from this point forward, the general guidelines are as follows. If they fail either test, they are referred for further evaluation. Children who fail the ABR at 60 dB or greater are referred for sedated ABR at 12 to 16 weeks of age. If they fail the sedated ABR at 60 dB or greater, they are referred immediately for behavioral audiometry, diagnosis, and habilitation. If they fail the sedated ABR at less than 60 dB, they are referred for further behavioral audiometry at 6 months of age.

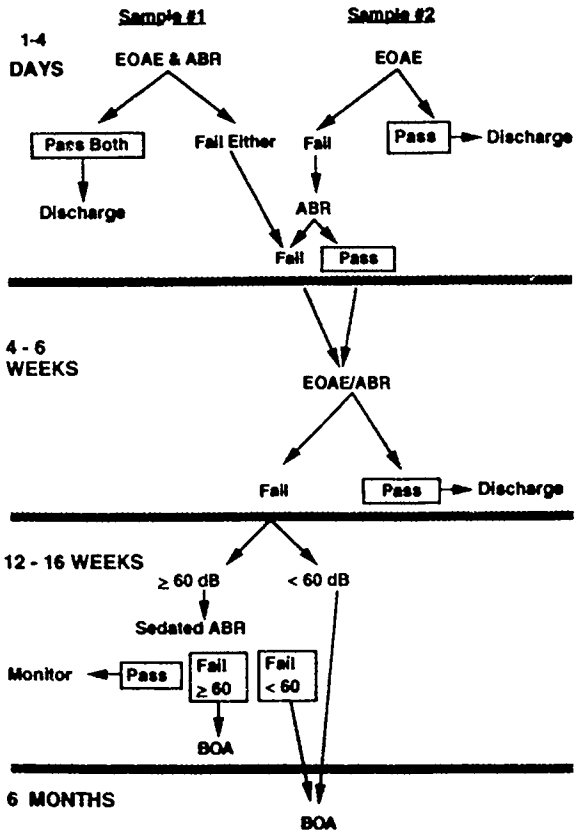

Figure 4. Design for the Rhode Island Hearing Assessment Project (RIHAP) hearing loss screening using evoked otoacoustic emissions (EOAE). ABR=auditory brainstem response; BOA=behavioral observation audiometry.

All children included in the sample were born at Women and Infants Hospital of Rhode Island (WIHRI). Approximately 70% of all births in the state of Rhode Island are at WIHRI. Because of the small geographical size of the state, virtually all children in the sample lived within a one-hour drive. At the present time, approximately 3,000 children have been screened. Because it took several months for

screeners to become proficient with the techniques, the data reported in this chapter are based on approximately 2,000 infants who were screened after the third month of the project and who are now old enough to have completed the sedated ABR testing if that was indicated. It should also be emphasized that the confirmation of hearing loss using behavioral audiometry will not occur for several months for most of these children. Thus, the results concerning hearing loss reported in this chapter are based primarily on the results of sedated ABR testing. Further information about confirmation testing will be contained in future reports.

DATA COLLECTION PROCEDURES

For EOAE screening, the ILO88 Otodynamic Analyzer (Kemp 1988) produced by Otodynamics, Ltd. was used. ABR screening was done using the GSI-55. Further information concerning the protocols for each test is available elsewhere (Maxon, White, Norton, and Behrens 1991).

Testing was scheduled by examining the log of births and expected release dates each day, identifying babies who were appropriate for testing, obtaining informed consent from their mothers, and coordinating the schedule of screeners with scheduled hospital procedures. Babies were brought by schedulers into a relatively quiet room to which acoustic tiles and room dividers had been added. The baby was placed in an isolette that could be closed, and testing was done by screeners who had been trained for that purpose.

Screeners with different types of training and experience were intentionally used (i.e., registered nurses, audiologists, and paraprofessionals). Extensive training was provided, and each potential screener had to complete a certification process before beginning screening. Regular monitoring of performance and, where necessary, corrective feedback were given by a certified audiologist.

Babies who failed the initial screen were invited back to the hospital at 4 to 6 weeks of age for further testing as depicted in figure 4. In those cases where transportation would be a financial hardship, the parents were reimbursed for travel costs. Letters were sent to the primary care physician for all children who failed the initial screen, and the help of the pediatrician was enlisted in those cases where it was difficult to get the parent to bring the child back. Approximately 70% of the children who failed the initial screen were successfully rescreened.

RESULTS

The results reported here are preliminary. Not only is further confirmatory testing being done with those children tentatively identified as having hearing losses, but additional children are being screened. This section summarizes the lessons learned thus far from the project concerning the conduct of a neonatal hearing screening program based on EOAE and provides preliminary information regarding the feasibility, validity, and cost-efficiency of doing mass neonatal hearing screening using EOAE.

PROCEDURAL LESSONS LEARNED

Because EOAEs have not previously been used in a large-scale neonatal hearing screening program, there are a number of valuable lessons that have been learned about conducting an EOAE screening program. Several of the most important lessons are summarized below.

Training and monitoring of screeners. Although the use of the EOAE screening equipment is simple and straightforward, it is absolutely essential that procedures be established for structured training of screeners (including didactic presentation of information, observation, and experiential learning), and that regular monitoring procedures be implemented thereafter. Unless such training and monitoring occur, there will be an unnecessarily high rate of invalid results. It is very unlikely that a child with a hearing loss will pass the screen if the testers are not using appropriate techniques, but there will be an unnecessarily high rate of false positives (children who fail the test even though their hearing is normal).

Qualifications and experience of screeners. Screeners with varying types of experience and qualifications were intentionally used to determine if some were more successful than others. A certified audiologist who had extensive experience testing babies observed each screener on a regular basis for adherence to the protocol and mastery of testing procedures, and data were collected for each screener about the percentage of children who failed or had uninterpretable results. Based on those data, no particular prior training or expertise is required to be a successful EOAE screener. Surprisingly, the category of screeners that turned over most frequently and encountered the most difficulty with the screening protocol was the certified audiologists—probably because the screening protocol limited their ability to function as an audiologist (i.e.,

they wanted to proceed beyond screening to diagnosis, habilitation, and work with the child and parent). In all cases, it was clear that expertise of the screeners improved dramatically with experience. Screeners who worked 20 hours or more per week were much more successful than those who worked fewer than 10 hours a week.

Time of testing. Children in the regular care nursery were tested at whatever time was convenient prior to being discharged. After an examination of the failure and pass rates for children according to their age in days when testing occurred, it was discovered that the failure rate was strongly correlated with the age at which testing occurred. Children tested within 24 hours of birth had a failure rate of 30%, while the failure rate for children tested three to four days following birth was only 18%. Thus, it is clear that the false positive rate (and thus the cost of the screening program) can be substantially reduced by scheduling screening sometime following the first 24 hours of birth but prior to the time that the child is released from the hospital.

Environmental noise. Although a soundproof room is not required for EOAE testing, environmental noise can interfere with testing if precautions are not taken. One of the most important sources of environmental noise comes from the baby. If testing can be conducted when the baby is in a quiet state, such as shortly after feeding, the time required to do testing is substantially reduced, and the pass rate is substantially increased. Testing was also more successful if it was done in an isolette that could be covered to block out other environmental noise in the room. The ILO88 equipment has built-in noise artifact rejection, but arranging to do the testing in a place that is reasonably quiet is well worth the effort.

Debris in the ear. Because they are tested so soon after birth, many babies had obstructions in the ear canal (e.g., vernix, wax, birthing debris), or their ear canals were partially collapsed. Based on a carefully controlled subsample, it was discovered that the failure rate could be reduced by as much as 60% by removing the debris from the canal or using the probe to "open" the canal. Because of time limitations and other logistical considerations, these procedures were not used for the majority of the babies in this data set, but they are procedures that should be considered as a part of the protocol in designing EOAE screening programs.

Scheduling and transportation. In budgeting for the EOAE screening program, it is critical to remember that babies will have to be transported from the nursery to the testing location, and someone will have to be responsible for coordinating all of the scheduling. In this project, scheduling and transportation required as much time and resources as actually doing the testing.

Increased community awareness—A fringe benefit. At the beginning of the project, letters were sent to all pediatricians in the community to explain the purpose and activities of RIHAP. Meetings were also held with the hospital staff (nurses, residents, administrators). After screening was initiated, letters were sent to the primary care physician whenever a baby failed the initial screen or any subsequent screen. In addition, when RIHAP staff experienced difficulty in scheduling a child for follow-up testing, the primary care physician was contacted to request assistance in having the parent bring the baby back for testing. Information about the project also appeared in the newspaper and on the local television news. The awareness created by these activities has had a substantial impact on early identification of hearing loss beyond the children actually identified through screening. Over the year and a half since RIHAP began, the enrollment in the infant program (birth to 2 years of age) at the Rhode Island School for the Deaf has more than quadrupled over the average enrollment for the past seven years. Officials at the school attribute this enrollment increase to the awareness in the community about hearing loss that has happened as a result of RIHAP.

FEASIBILITY OF USING EOAE IN NEONATAL HEARING SCREENING

Thus far, the project has screened over 3,000 babies, including children in regular and special care nurseries. The average time required to do screening has been 12 minutes per child in the regular care nursery and 14 minutes per child in the special care nursery. Approximately 18% of the children in the regular care nursery fail the initial screen and are referred for further testing, while 25% of the children in the special care nursery require further testing.

The project has clearly demonstrated that it is possible to screen large numbers of infants (as many as 25 per day). It is feasible to manage the logistical and procedural details of scheduling infants for testing, transporting them to the testing location, coordinating screening with necessary medical procedures, and accomplishing the testing prior

to discharge. With the trend toward shorter stays in the hospital, a few babies will be missed. But the results of this project demonstrate that EOAE techniques can be used to screen over 95% of all babies in regular and special care nurseries.

VALIDITY OF USING EOAE IN NEONATAL HEARING SCREENING

Although the data reported here are preliminary and information about hearing loss is, in many cases, based only on the results of the sedated ABR, EOAE appears to be a very promising technique for use in screening programs to identify hearing loss. Considering those data collected after the time that the operational procedures for the project were refined, just under 2,000 babies have been screened and are now old enough to have received a sedated ABR if one was indicated. Based on that sample, 9 children with suspected sensorineural hearing loss and 12 children with fluctuating conductive hearing losses have been identified. Thus, the EOAE screening program is identifying almost 5 children per 1,000 with a sensorineural hearing loss. This prevalence of sensorineural hearing loss is two to three times what is typically expected in the general population (Bergstrom 1982; Parving 1985). This is strong evidence that EOAE can be successfully used to identify children who have a hearing loss.

If only the sample of children who received both an EOAE and an ABR at the initial screen is considered, the agreement between initial EOAE and initial ABR is quite good as shown in figure 5. The agreement between initial EOAE and rescreen ABR and rescreen EOAE and rescreen ABR is even better.

About half of the children with suspected sensorineural hearing loss would not have been identified using other typically used approaches to early identification. Four of the nine children with suspected sensorineural hearing losses exhibited none of the high-risk factors recommended by the Joint Committee on Infant Hearing (1983), and six of the nine children did not spend any time in the special care nursery. Thus, a screening program that focused only on children who exhibited one or more of the risk factors or children in a special care nursery would have missed a substantial number of these children. One of the nine children identified through EOAE would not have been identified based on the results of the initial ABR.

Initial ABR

		Fail	Pass	
Initial EOAE	Fail	50	162	Sensitivity=60%
	Pass	34	826	Specificity=84%

(only includes infants who received both tests regardless of results)

Rescreen ABR

		Fail	Pass	
Initial EOAE	Fail	31	210	Sensitivity=91%
	Pass	3	79	Specificity=27%

Rescreen ABR

		Fail	Pass	
Rescreen EOAE	Fail	30	40	Sensitivity=94%
	Pass	2	215	Specificity=84%

Figure 5. Agreement between evoked otoacoustic emissions (EOAE) and auditory brainstem response (ABR) (data based on ears for period from June 1, 1990, to April 30, 1991).

All of these children were identified as having a suspected sensorineural hearing loss before 4 months of age. Although final confirmation of hearing loss must be based on the results of behavioral testing, it is expected that such confirmation will happen well before the goal of 12 months established by the U.S. Department of Health and Human Services (1990) in the *Healthy People 2000* goals.

COST-EFFICIENCY OF USING EOAE IN NEONATAL SCREENING

The cost of screening every live birth using EOAE will vary to some degree depending on the specific protocol used, who does the testing, and the prevailing pay-scale in a particular location. For example, if screening is done by audiologists or registered nurses, it will be much more expensive than if paraprofessionals are used. Furthermore, if ABR testing is routinely incorporated as a part of a 4- to 6-week rescreen, the

cost of screening will be more expensive than if only EOAE is used at both the initial screen and the subsequent rescreen.

Using an ingredients approach to cost-analysis (Levin 1983), we estimated the costs of a screening program similar to RIHAP using paraprofessionals to do all testing and using only the EOAE at both the initial and the rescreen tests. Including the costs of screening, scheduling and transportation, coordination, and training and monitoring of the project by an audiologist, the cost of such screening would be approximately $20 per child. Thus, the cost of identifying each child with sensorineural hearing loss is approximately $4,500.

Precise information is not available about the benefits of identifying children with sensorineural hearing loss at 6 months of age instead of 24 to 30 months of age (as is currently the case). However, given the devastating consequences on all aspects of life of not acquiring appropriate language skills, it seems that this initial cost of identification would be easily recovered in terms of reduced costs for special education, increased productivity, and more complete participation in society. Further analyses of the cost-benefit ratios are clearly needed, but the costs of identifying sensorineural hearing loss in children in this project certainly seem reasonable. If one considers the benefits of also identifying children with conductive losses earlier, the cost-benefit ratios are even more favorable.

SUMMARY

There is universal agreement that significant hearing loss should be identified as early as possible, preferably before 12 months of age (American Speech-Language-Hearing Association 1989; U.S. Department of Health and Human Services 1990). Unfortunately, existing techniques, such as the use of high-risk registers, ABR testing, or behavioral screening, have not been successful in identifying the majority of children in the United States with significant hearing loss at such a young age. The Rhode Island Hearing Assessment Project (RIHAP) was designed to evaluate the use of evoked otoacoustic emissions (EOAE) in a mass neonatal hearing screening program. Based on the data collected thus far, the preliminary results are encouraging.

Using the EOAE techniques, approximately two to three times as many children with a suspected sensorineural hearing loss have been identified as would typically be expected. The results of the EOAE agree

substantially with the results of ABR screening for those children for whom both tests were done. Furthermore, about half of the children identified using EOAE did not exhibit any of the 1982 high-risk criteria and would not have been identified using ABR screening methods with high-risk children or children in a special care nursery. The fact that the results of this project demonstrate that EOAE is feasible to use in a screening program for every live birth clearly demonstrates that this technique deserves further investigation and evaluation.

Much additional research is necessary before concluding that EOAE is the screening technique of choice. The data reported in this article are preliminary, yet promising. The project continues to screen children so that the sample sizes will be larger, many of the results reported here concerning hearing loss are based only on sedated ABRs and must be confirmed through behavioral testing, and further analyses will be done after the sample sizes are complete. Nonetheless, this project demonstrates the feasibility of implementing such a program and suggests that a substantial number of hearing-impaired children, who otherwise would have been missed, are being identified using EOAE-based screening. The cost of such a program is reasonable compared to other screening programs.

Since this is the first effort in the United States to implement EOAE screening on a large scale, many questions still remain. Not only should the additional data collection and analysis referred to above be conducted, but it is important that other sites replicate the techniques used in RIHAP. Additional questions remain concerning the exact nature of the protocol to be used; techniques for reducing the relatively high rate of false positives; who should do testing; and how results should be scored and interpreted. In spite of the need for further research and refinement, the results of this project suggest that EOAE is a viable and promising technique for use in neonatal hearing screening programs.

ACKNOWLEDGMENTS

Supported in part by project #MCJ-495037 from the Maternal and Child Health program (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.

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Chapter 16

Sensorineural Hearing Loss in High-Risk Infants

Diane L. Sabo, David R. Brown, and Jon F. Watchko

INTRODUCTION

Sensorineural hearing loss continues to be a serious long-term neurodevelopmental sequela of neonatal intensive care. The prevalence of hearing loss is estimated to be between 2.5% and 10% among infants who manifest any of the risk factors recommended by the 1982 Joint Committee on Infant Hearing (Anagnostakis et al. 1982; Astbury et al. 1983; Bergman et al. 1985; Duara et al. 1986; Pettigrew, Edwards, and Henderson-Smart 1988; Salamy, Eldredge, and Tooley 1989; Stein et al. 1983). Hyperbilirubinemia (Bergman et al. 1985; de Vries, Lary, and Dubowitz 1985; Perlman et al. 1983; Vohr, Lester, and Rapisardi 1989; Wennberg et al. 1982), perinatal asphyxia (Duara et al. 1986; Barden and Peltzman 1980), and the general medical condition of the infant (Bergman et al. 1985; Duara et al. 1986; Pettigrew et al. 1988) have been implicated as the causes of sensorineural hearing loss without consensus being reached. Therefore, we studied 35 children with sensorineural hearing loss and 70 matched controls to determine the independent effects of conventional risk factors for hearing impairment.

METHODS

Auditory brainstem responses (ABRs) have been used at Magee-Womens Hospital since 1980 as a screening method for hearing loss. Infants were selected for screening based on 1982 Joint Committee's risk

(1991, Summer). That's my baby, pp. 14-15, 53. Portland, OR.

Can Your Baby Hear?

Now Oregon Has a System to Help You Know

by Jean A. Josephson

During a lunch date with his mom, a little boy picked up his grill cheese sandwich and asked, "Why do we always have grill cheese instead of boy cheese sandwiches?"

Lucky are the babies born in Oregon. We are one of only a small number of states actively on the lookout for infants with hearing impairments. Why are we deliberately trying to find these newborns? Because there's one sure rule in identifying childhood hearing impairment: the sooner the better.

Babies need to hear before they learn to listen and to speak, especially during their critical years of language acquisition—birth to age three. If their hearing isn't normal, and special intervention isn't begun, they will suffer needless delays in their language, psychosocial, educational and vocational development. Babies with hearing impairments who are identified before their first birthday have a greater opportunity to develop language skills (either spoken or signed) and reach their full potential of social and educational development.

While the odds are in favor of your baby having normal hearing, no baby's hearing ability can be taken for granted. The incidence of hearing loss in newborns is 1 in 1000, and is one of the most common infant disabilities in the United States. Because so many hearing-impaired infants are in all other ways healthy, you can't tell by looking whether or not they can hear. It is, in fact, difficult to assess an infant's hearing unless you are very knowledgeable about infant development and have experience evaluating infant communication behaviors. Parents are generally excellent observers of their own baby's behavior, but rarely suspect hearing problems until well into their baby's second year of life. If there is a hearing impairment, more than half of the critical language learning period is lost by the time most parents begin early intervention services.

Several years ago, the Oregon Health Division recognized the need to identify hearing loss in infants—before their first birthday. Our birth certificate was revised in 1989 to include questions about family history of childhood deafness, infant admittance to a neonatal intensive care unit, and other known indicators, called risk factors, that make some babies more likely than others to have hearing problems. In August, 1989, with help from the federal Bureau of Maternal and Child Health, Oregon began screening for risk factors for hearing impairment using birth certificates.

Information about your baby's birth is collected by the hospital and entered on the legally mandated birth certificate. A nurse, records clerk or hospital volunteer asks you your baby's name, but probably even more importantly, needs to know if there is a family history of childhood hearing loss. Medical information surrounding your pregnancy and delivery are recorded using hospital records. Completed birth certificates are filed at the county vital records department, and then at the State Health Division. Accurate information on the birth certificate is crucial to your access to services provided by the Health Division.

Birth certificates are screened and babies with a risk factor for hearing loss are sorted and identified. About five months after the birth, parents of at-risk infants receive notices from the Health Division, alerting them to the need for hearing screening. Since one out of every ten babies has a risk factor, many notices are mailed each month. Parents can choose to set up their own appointment with an audiologist—a professional who has the training and equipment to accurately and reliably test hearing, or they can request that a public health nurse assist them in making an appointment. Of course the program is voluntary, and parents can choose to not have their baby's hearing tested.

However, as the parent of a child with a hearing impairment who was two years old before she was finally diagnosed, I urge you to respond to the advice by having your baby's hearing tested. Our thriving infant gave us few clues that her hearing wasn't normal. She smiled warmly, slept soundly, said "mmmmm" when she liked her food, and called her teddy bear "Ba." But she didn't always turn her head when I called her name. She often continued to stare at the mobile on her crib when I stood at her doorway and sang a cheery "hello" after nap time. She had fewer words than her 18-month-old play group friends. I did wonder if something was wrong, but she always jumped when I slammed the door and she did have a vocabulary, so I dismissed the idea that she couldn't hear.

An observant friend forced my anxiety levels to the point that I made my own appointment to have our two-year-old daughter's hearing tested, just so I could stop worrying. The news that she had a significant hearing loss was a shock, and a relief. Deafness is a very scary word to those who know little about the condition, but we learned fast. We got into a program for the hearing-impaired and received the needed educational and emotional support.

That was 12 years ago—before systematic programs to identify hearing-impaired infants and heightened medical awareness about the need for early identification were getting much attention. Now, our Health Division's screening program—called the Oregon Newborn Hearing Registry—will potentially identify between 60% and 80% of all infants with hearing impairments. If you get a letter, or if you know your baby has a risk factor, have his/her hearing tested.

How do you know if your baby's language development is on schedule? Moms in Oregon hospitals are given lavender-colored packets of information about immunization, birth certificates and now, developmental guidelines. There's a card inserted in the packet, titled *Parents are the First to Know if Their Infants Cannot Hear.* Behaviors appropriate for different ages are described.

Hearing can be tested at birth. Let me repeat this. . . *hearing can be tested at birth!* Our second child was tested before she went home from the hospital. Because her big sister gave her a "family history of childhood hearing loss," she was at risk. From experience, we knew that not a moment of language learning time could be lost. Tiny electrodes were taped to our sleeping newborn and computers measured her brain's responses to sounds. She passed her first test, but we continue to monitor her hearing: sometimes this hearing test, called an ABR (Auditory Brain Stem Response), can be inconclusive for neonates; and some hearing losses are progressive.

The Oregon Newborn Hearing Registry recommends that babies with risk factors, who appear to be developing normally, have their hearing tested at about six months of age. Premature babies are tested when they reach an adjusted age of six months. Audiologists use a behavioral hearing test, called VRA (Visual Response Audiometry), that's less expensive and more widely available than the ABR test. The baby sits on his or

(continued on pg. 53)

(continued from pg. 15)

her parent's lap, is alert, and is usually entertained by the 30-minute procedure. Audiologists around Oregon know the importance of early identification of hearing loss, and most of them will test babies for free if the family has no means of payment. There are good services across the state for infants with hearing impairments and their families. Public and private agencies provide specialized instruction and support.

No parent chooses to face the issue of infant hearing loss, but every parent wants to do what's best for the baby. Be alert and be aware. Learn and chart your baby's language development milestones, just as you keep track of when he or she began to crawl or learned to walk. Be certain that every moment of your baby's precious language-learning time is well spent. And be glad that you live in a state that has a hearing screening program and good services for infants with hearing impairments.

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Risk Factors for Hearing Impairment in Newborns

- Family history of congenital or delayed-onset childhood sensorineural impairment.
- Congenital infection such as toxoplasmosis, syphilis, rubella, CMV and herpes.
- Abnormalities of the head or neck
- Birthweight less than 1500 grams (3.3 lbs.)
- Hyperbilirubinemia at level exceeding indication for exchange transfusion.
- Bacterial meningitis.
- Apgar score of less than 6 at 5 minutes
- Admittance to a neonatal intensive care unit.

(1991). The Volta Review, 93(4), 187-196.

Identification of Children With Hearing Impairments: A Baseline Survey

William G. Moore, Jean A. Josephson, and Gary W. Mauk

In 1989, Oregon initiated a birth certificate screening program to identify newborns with potential hearing loss. To provide baseline information against which to measure the effects of such a program, the present study was conducted. It was designed to determine the age and patterns of identification of children with hearing impairments prior to the implementation of the birth certificate screening program.

Data are presented on identification patterns, as reported by their parents and guardians, of 46 children with hearing impairments who turned 6 years of age during the 1989 calendar year. All but one of the children were enrolled in a public school program for pupils who are hearing impaired. Information on age of suspicion of hearing loss and age of confirmation of hearing loss are presented. Results indicate that the average age for identification of a hearing loss with the group was 30.6 months, which is nearly identical to the nationally reported average of 30 months. Risk factors associated with hearing impairments are discussed. Responses from medical professionals to parental queries regarding auditory developmental behaviors are examined. The need for early identification and habilitation of children with hearing impairments is discussed.

The most recent and best known census data on Americans with hearing loss was the National Census on the Deaf Population (NCDP) conducted in 1974 (Schein & Delk, 1974). The NCDP estimated that over 1.7 million persons were deaf, and that more than one tenth of them lost their ability to hear before age 3. Early identification of hearing loss is universally recognized as a necessary component to successful management of children with hearing impairments (Blake & Hall, 1990). Children who have prelingual hearing impairments experience delays in communication, education, and psychosocial development (Bess & McConnell, 1981; Downs, 1986; Levitt & McGarr, 1988; Schum, 1987). However, when hearing impairments are identified within the first few months of life, intervention that enhances the child's life can be implemented. If early identification procedures were more broadly executed, the majority of children with hearing-impairments in this country could be diagnosed shortly after birth, thereby gaining the advantage of intervention during the sensitive language acquisition period from birth to 2 1/2 years of age (Lenneberg, 1967). For example, children with hearing impairments who receive intervention before 2 1/2 have significantly better communicative skills than children who receive similar intervention at later ages (Clark, 1979). In recognition

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negative consequences of delayed identification of significant hearing loss, the Joint Committee on Infant Hearing (American Academy of Pediatrics, 1982) recommended that hearing loss be identified by 3 to 6 months of age. Improved communication skills are crucial to future psychosocial, educational, and vocational development.

Average Ages of Confirmation of Hearing Loss

The American Academy of Otolaryngology Head and Neck Surgery (1990) reports that in the United States, about 5,000 infants are born annually with a handicapping hearing loss and the average age for identifying their problems is about $2\frac{1}{2}$ years. Similarly, a report released in 1988 to the President and the United States Congress by the Commission on Education of the Deaf purports that, "the average age of identification for profoundly deaf children in the United States is $2\frac{1}{2}$ years."

In Israel and the United Kingdom, countries that have neonatal screening for hearing impairment, the average age for confirmation of hearing impairment is approximately 7 to 9 months (Gustason, 1987, The Lancet, 1986). These data suggest that some form of neonatal screening is an effective procedure for lowering the age at which infants with hearing impairments are identified.

Early Identification by High-Risk Registry

Neonatal screening programs have been established in several states in this country (Blake & Hall, 1990). Some of these programs collect screening information in conjunction with birth certificate data. One of the oldest and best established of these screening programs is conducted by the Utah Department of Health (Mahoney, 1986). Established in 1978, this system uses birth certificate data to acquire information about the occurrence of seven risk factors. The following seven factors are considered to be the most indicative of a potential hearing loss and were selected by the Joint Committee on Infant Hearing (American Academy of Pediatrics, 1982):

1. A family history of childhood hearing-impairment.
2. Congenital perinatal infection (e.g., cytomegalovirus, rubella, herpes, toxoplasmosis, syphilis).
3. Anatomical malformations involving the head or neck (e.g. dysmorphic appearance including syndromal and nonsyndromal abnormalities, overt or submucous cleft plate, morphologic abnormalities of the pinna).
4. Birth weight less than 1500 grams.
5. Hyperbilirubinemia at level exceeding indications for exchange transfusion.
6. Bacterial meningitis, especially Hemophilus influenza.
7. Severe asphyxia (often measured with Agpar scores between 0 and 3 or infants who fail to institute spontaneous respiration by 10 minutes and those with hypotonia persisting to 2 hours of age).

In June 1989, the Office of Maternal and Child Health funded a project for Oregon to replicate the Utah birth certificate screening system. The intent of this effort is to lower the age of identification of children with hearing loss in Oregon.

Prior to the implementation of birth certificate screening, Oregon did not have a systematic procedure for identifying infants at risk for hearing loss. To determine the impact of the newly implemented protocol, the present study was conducted on a group of children with identified hearing impairments who had attained school-age during the 1988-89 school year. The purpose of this investigation was to determine the patterns of identification of hearing loss in these children.

Table 1. Range of hearing loss at time of diagnosis of children identified in study.

Range	*Number of Children*
Mild to Moderate	20
Moderate to Severe	10
Profound	16

Method

Potential participants were all 6-year-olds with hearing impairments enrolled in Oregon's educational programs for hearing-impaired children during the 1989 calendar year. They were identified by the Oregon Department of Education. A total of 58 children were identified.

To determine if the parents wished to participate in the study, the childrens' schools contacted the 58 families by mail. The letters included a description of the study, the type of information desired from them, and a post card they were to return if they did not wish to participate. A total of 51 families, representing 51 children, agreed to participate.

Information needed from each participating family was acquired using a telephone interview questionnaire. The questionnaire was revised from a similar instrument developed in Utah. The interviewer had a master's degree in deaf education and 6 years teaching experience. When the interviewer contacted the parents, they were given the option to complete the interview at that time or to arrange a more convenient time. All interviews were conducted during April and May, 1990.

Results

Reliable surveys were completed on 46 children. Thirty-six (78.3%) of the children were born in Oregon. All but one were enrolled in a public school program in Oregon; this one child attended a private school. Table 1 presents the range of hearing loss of the 46 children at the time of the diagnosis. Four children were reported as having a progressive hearing loss.

Data were analyzed with respect to: (a) auditory-related behaviors of children with hearing impairments, observed or not observed, by parents and guardians during their children's first 12 months of life; (b) the professionals contacted by parents for assistance; (c) average age of suspicion of hearing loss; (d) average age of confirmation of hearing loss; (e) average age of habilitation; (f) average age of amplification; and (g) risk factors associated with hearing loss.

Parental Observation of Hearing Behaviors. The following percentages of parents and guardians responded affirmatively to these statements concerning their child's hearing history:

Birth to 3 Months: 63%–Child did not startle or jump when there was a sudden loud sound.
70%–Child did not stir or awaken from sleep or cry when someone talked or made a noise.
41%–Child did not recognize and was not soothed or comforted and not pacified by the sound of mother's or

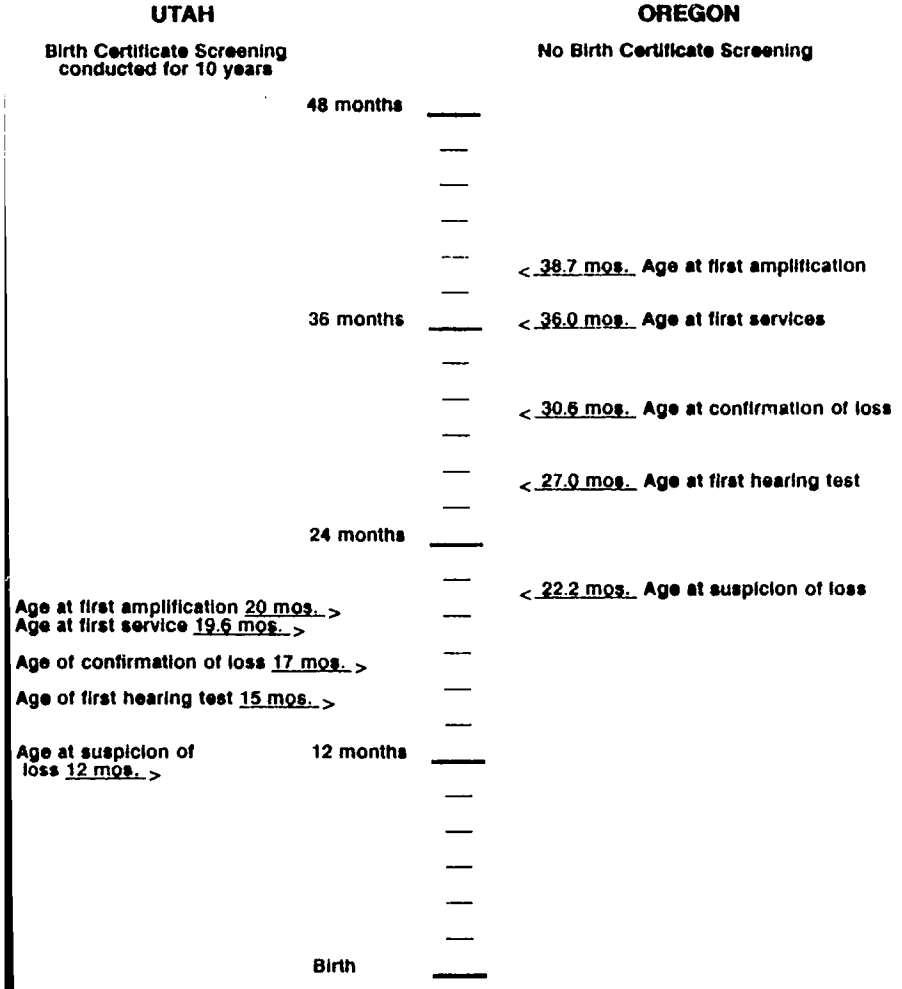

Figure 1. Mean Ages at which children with hearing-impairments in Oregon and Utah are identified and assisted. (August, 1990)

other familiar voice.

3 to 6 Months:
- 41%–Child did not turn eyes to look for an interesting sound.
- 30%–Child did not respond to mother's voice.
- 51%–Child did not turn eyes forward when name was called.

6 to 12 Months:
- 67%–Child did not turn toward interesting sound and did not turn toward parent when his/her name was called from behind [sound did not have to be loud].
- 43%–Child did not understand "No" and "Bye-Bye" and other common words.
- 59%–Child did not search or look around when new sounds were present.

When queried as to what specific behavior during the first 12 months alerted them to a possible hearing loss, 22% of the parents reported their child did not turn to a sound, 11% didn't startle, and 4% did not wake to sound. The majority of parents, 59% (n=27) reported that no behavior during the first 12 months of life alerted them to a possible hearing impairment.

From Suspicion to Habilitation. The mean age of parental suspicion of a hearing loss was 22.2 months. The mean age for the child's first hearing test was 27.0 months (a 4.8 month delay) while the mean age at confirmation of a hearing loss was 30.6 months (a 3.5 month delay from first test to confirmation). The mean age at first habilitation (e.g., parent-infant program, speech-language services) was 36 months (a 5.5 month delay from confirmation). Finally, the mean age at first amplification was 38.7 months (a 2.7 month delay from the onset of service).

These results are presented in Figure 1 and are compared with similar data from Utah. These data indicate that, on the average, children in Utah are receiving service and amplification before children in Oregon are even suspected of having a hearing loss.

Accessing and Utilizing Professionals. Parents were asked whom they first contacted when they suspected their child might have a hearing loss. The majority, (n=22), reported that they contacted a pediatrician or general practitioner. Audiologists were contacted by 16 parents and seven parents visited an otolaryngologist.

Of the parents who consulted a pediatrician or general practitioner, four reported that their child's hearing was tested and eight recalled that they were referred to a specialist. Another eight reported that they were told that nothing was wrong and they should not worry. Fifteen of the 16 parents who saw audiologists recalled that their child's hearing was tested; one reported referral to a specialist.

Four of those who sought the advice of an otolaryngologist recalled that their child was tested and another stated that the family was referred to a specialist. One parent was told that nothing was wrong and not to worry.

The interviewer asked if the parents were satisfied with the advice they had received. Of the parents who visited a pediatrician or general practitioner, fourteen (64%) reported they were satisfied, eight (88%) of the parents who visit an audiologist reported satisfaction with the advice they received, and five (71%) of the parents who visited an otolaryngologist reported satisfaction.

Risk Factors and Hearing Loss. Thirty-three (72%) children manifested at least one of the seven risk factors identified by the Joint Committee on Infant Hearing (American Academy of Pediatrics, 1982). One-third of the parents (n=11) of these children reported a history of family childhood-onset hearing loss.

2. Hearing-impaired 6-year-olds in Oregon: Mean ages of historical hearing events for n with and without at least one risk factor.

	High Risk	*Not High Risk*
	Hearing-impaired children with at least one risk factor (n=33)	*Hearing-impaired children with no risk factor (n=13)*
Event	*Mean Age (in months)*	*Mean Age (in months)*
Suspicion of Loss	18.4 (SD=15.7) R=1-48	26.7 (SD=17.7) R=1-60
Hearing testing	25.5 (SD=18.3) R=1-60	31.0 (SD=15.4) R=6-60
Confirmation of Loss	29.5 (SD=20.8) R=1-66	32.4 (SD=15.1) R=6-60
Habilitative Services	35.0 (SD=23.1) R=2-75	38.9 (SD=19.8) R=6-72
Amplification	38.5 (SD=23.3) R=2-78	38.9 (SD=19.8) R=6-74

SD = Standard Deviation (in months)
R = Range (in months)

All children with at least one risk factor for a hearing loss (n=33), hereafter identified as "high risk," were compared on hearing milestones with the 13 children with no risk factor for hearing loss, hereafter identified as "not high risk."

The mean age of confirmation of a hearing loss in the two groups was examined and found to be earlier in the high-risk group, but only by 3.5 months. Even with a risk factor present, the mean age of identification for this group was 27.3 months of age.

As shown in Table 2, a comparison of the mean ages of historical hearing events indicates that the mean age for suspicion of a loss is 8 months earlier in the high-risk population. The high-risk population had their hearing tested 5 $^1/_2$ months earlier. Data on the next three events indicate that differences between the two groups became narrower. The mean ages of initiation of habilitative service and amplification for both groups is near or greater than 3 years.

Discussion

The purpose of this study was to determine the age at which children in Oregon were identified as having a hearing impairment. Results indicate that the average age of identification was 30.6 months. This is comparable to the national average of 30 months (Commission on Education of the Deaf, 1988; American Academy of Otolaryngology - Head and Neck Surgery, 1990). These data provide a baseline by which Oregon can measure the impact of the newly-established birth certificate screening program. Continuing studies over time must be conducted before definitive statements can be made about the long-term success of the screening program.

Additional findings in the study regarding parental awareness of hearing-related behaviors and the benefits of early identification may be instructive in program planning. Results indicate that some parents did notice the absence of behaviors that would suggest a possible hearing loss in their child during the first 12 months of life. However, more parents did not equate the absence of critical auditory-related behaviors with the possibility of a hearing loss. Nearly 60% of the parents reported that no behavior in the first 12 months alerted them to their child's hearing loss. But on the average, by 22.2 months, 50% of the respondents and 11% of their spouses were identified as the persons who suggested that the child's hearing be tested.

Of additional concern is the delay from when the parent first suspected a hearing loss to when the child received amplification. The average delay was over 16 months. With amplification not occurring, on the average, until the child was past 3 years of age, precious time for speech and language development was lost. One can only speculate why parents did not equate the absence of critical behaviors with a hearing loss or why they waited so long to act upon their suspicions.

Several studies have reported similar findings. Not responding to the absence of critical hearing-related behaviors may be an indication of denial or rationalization on the part of the parent (Mindel & Feldman, 1987). Parents reported that feelings can blur perception through a psychological denial that disregards certain elements of the child's total behavior. The parent may ignore the child's failure to respond to voices and instead notice the child shift his or her gaze toward a door that has just been closed, attributing this to a perception of sound rather than to the strong vibration transmitted through the floor or the blocking of incoming light. In addition, parents may rationalize that the child is "just being stubborn" or "hearing what he wants to hear."

Mindel and Feldman (1987) also report that regardless of the child's age, a period of shock follows the parent's learning that their child is deaf. The shock is a blend of disbelief and grief, helplessness, anger and guilt. They state that a person thrust into such a state suddenly feels set apart from others. As parents experience these feelings and devote time and energy to overcome them, they may put aside the need to acquire the professional assistance their child needs. Research suggests that parents may need more than education. Mindel and Feldman (1987) found that parents benefitted through parent-to-parent interaction with other parents of children who were deaf. Further examination is needed to determine the best approach to educate and assist parents with young children with hearing impairments.

As reported in the present study, not all parents received accurate or correct assistance from the professional they first contacted. This is most apparent for the 22 parents who consulted a pediatrician or general practitioner. Over 63% of these parents were satisfied with the advice they received from these professionals. Yet more than 36% of them were told not to worry and/or that nothing was wrong with their child's hearing. This incorrect advice from the professional adds to the delay in diagnoses. Others have reported similar findings (Matkin, 1987):

> Parents typically express their initial concern about developmental delays to the child's physician, who may ignore them. It is imperative that pediatricians and family practitioners become better informed about early signs of hearing loss, especially speech-language delay.

> Physicians also must be encouraged to respond positively to parent's observations that something is different about their child's development and refer the child for an evaluation of sensory function and development. The frequent recommendation to "wait and see if he outgrows it" is an inappropriate response (p. 43).

In a survey of parents of children with hearing impairments, Sweetow and Barrager (1980) reported that 56% of them had initially been assured, usually by a pediatrician, that their child probably did not have a hearing impairment. In a similar study, Shah and Wong (1979) found that parents are alert to their child's hearing-impairment by about 1 year of age but many physicians dismiss parental suspicions as invalid or do not regard parental observations as indicators for referral and testing. Data from the present study, as well as from others, indicate a need to educate both parents and professionals about early signs of hearing loss.

Results presented in Table 2 indicate that the presence of a risk factor for a hearing loss did not guarantee early identification and habilitation. Children with a risk factor were suspected of having a hearing loss and were tested on the average, six to eight months earlier than children without a risk factor. Even with the presence of a risk factor some of the children were 5 years of age before they had their first hearing test.

Furthermore, there was an average difference of only four months or fewer between children with a risk factor and those without, in each of the areas of confirmation of a loss, and initiation of habilitative services and use of amplification. In some cases, habilitative services did not commence until after 6 years of age for children with a risk factor. One can speculate why this has occurred. Physicians may not have associated the presence of a risk factor with potential hearing loss. In addition, they may not share with the parent that a risk factor is present and thus the parent is unaware of the potential for a hearing loss. Shah and Wong (1979) reported in their study of preschool children with hearing impairments that risk factors were present in 62% of the cases. Common factors were rubella, birth problems, including low birth weight and prematurity, meningitis, a family history of childhood deafness, Rh incompatibility and hyperbilirubinemia. Only 34.7% of the parents of these children were advised of the risk by their physician at the appropriate time.

Conclusion

Results of this investigation confirm that children with hearing impairments in Oregon are identified at approximately the same average age, 30.6 months, as children nationally, 30 months. It is hypothesized that this age of identification can be lowered with birth certificate screening for risk-factors for hearing loss. In Utah, where birth certificate screening has been operational for over 10 years, children, on the average, are receiving services before children in Oregon are suspected of having a loss. Studies similar to the present one will need to be conducted in the future to determine the actual impact of Oregon's newly established screening program. Results obtained in the present study provide baseline data for these future efforts.

During the first 3 months of their child's life, the majority of parents noticed the lack of behaviors related to hearing performance and they continued to observe these deficiencies. These findings suggest that parents do observe the lack of critical hearing behaviors in their child but they fail to associate them with a potential hearing loss. Parents need to be given relevant child development information and they need to be alerted to the possible consequences when development does not occur as predicted. They should also be alerted to the possible repercussion of risk factors. Information of this variety could be given to parents in some type of written format at the hospital at the time of birth. In addition, a verbal explanation could also be provided by a nurse or physician.

Parents need to be assured that the medical community will respond appropriately to their concerns when they are voiced. Physicians and other health care providers need to be alert to the signs of a possible hearing loss and then must respond correctly. Results of the present study suggest that one of the most appropriate responses would be a referral to an audiologist.

The national goal (U.S. Department of Health and Human Services, 1990) is to identify children with hearing impairments when they are infants, prior to 12 months if possible. If we are to be successful, responsibilities must include:

1) alerting parents to the developmental sequence of auditory-related behaviors and re-emphasizing this information to the medical community;
2) publicizing the risk factors for hearing loss and the consequences of such loss;
3) identifying from birth certificate screening which infants are at risk for hearing loss, and;
4) emphasizing appropriate responses to concerns about hearing and the need for expedition in determining hearing status.

Resources for habilitating infants with hearing-impairments and their families are available in Oregon. Getting these infants identified and into services sooner is the goal.

In summary, birth certificate screening for risk factors and the subsequent notification to parents alerting them to the need for hearing testing should help overcome one of the identified problems. Getting parents to respond appropriately to the information they receive is critical. Encouraging professionals to respond to high-risk status and to parental concerns about hearing by arranging audiological evaluation in a timely manner must be a priority.

ACKNOWLEDGEMENTS

Preparation of this manuscript was supported in part by a grant to Utah State University from the United States Department of Health and Human Services, Public Health Services, Grant #MCJ-495037-01. We are appreciative of the assistance provided by Karl White, Ph.D., Utah State University and that of Thomas Behrens, Ph.D., Special Assistant to the Assistant Director, Office of Special Education & Rehabilitation Services, Washington, DC. We are also grateful to Mr. Bruce Bull who directed the parent telephone survey.

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Reprint No. 91-B

Headquarters: The Volta Bureau
3417 Volta Place, N.W., Washington, D.C. 20007
Printed in U.S.A.

Seminars in
HEARING

Volume 14, Number 1 February 1993

The Rhode Island Hearing Assessment Project: Implications for Universal Newborn Hearing Screening

Karl R. White, Ph.D.
Thomas R. Behrens, Ph.D.

PREFACE

Mark Twain once lamented the fact that even though everyone complains about the weather, nobody does anything about it. Twain's comment is uncomfortably reminiscent of our efforts to substantially reduce the age at which hearing impairment is identified among young children in the United States. On the average, children in the U.S. with severe to profound hearing impairment are not identified until approximately two and one-half years of age--far too late. Children with milder but, nonetheless, significantly detrimental hearing losses are frequently not identified until they are five to six years of age. Unfortunately, even though everyone agrees that any hearing loss should be identified before 12 months of age; even though dozens of governmental commissions, task forces, and advisory groups have recommended immediate action; and even though millions of dollars have been spent on hundreds of research projects, little--if any--progress has been made during the last 40 years towards the goal of identifying children with significant hearing impairment before 12 months of age.

The importance of early identification of hearing loss was recently reemphasized in a report issued by the U. S. Department of Health and Human Services (1990), entitled Healthy People 2000. In this report, the federal government established goals to substantially improve the health of this country's citizens by the end of the decade. One of those goals is to **"reduce the average age at which children with significant hearing impairment are identified to no more than 12 months"** (p. 460). The importance of reducing the age at which significant hearing impairment is identified is summarized by the report as follows:

> The future of a child born with significant hearing impairment depends to a very large degree on early identification (i.e., audiological diagnosis before 12 months of age) 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. When early identification and intervention occur, hearing impaired children make dramatic progress, are more successful in school, and become more productive members of society. The earlier intervention and habilitation begins, the more dramatic the benefits. (p. 460)

Given the fact that so little progress has been made during the last 40 years in reducing the age at which hearing impairment is identified, simply trying harder or doing more of what we have been doing is not the answer. New approaches, different techniques, and more successful interdisciplinary cooperation are needed to substantially reduce the average age at which significant hearing impairment is identified. This issue of **Seminars in Hearing** is about such an approach. Begun in 1990 with funding from the Office of Special Education Programs from the U.S. Department of Education and the Bureau of Maternal and Child Health of the U.S. Public Health Service, the Rhode Island Hearing Assessment Project (RIHAP) was designed to systematically evaluate the feasibility, validity, and cost efficiency of using a recently introduced technique, transient

evoked otoacoustic emissions (TEOAE), to screen[1] infants for hearing loss. The results have been extraordinarily interesting, promising, and provocative.

- **Interesting** because even though the TEOAE method had been suggested since the early 1980s as a potentially viable method for newborn hearing screening, the results from RIHAP provide evidence from the first large-scale prospective clinical trial with babies from both normal-care nurseries and neonatal intensive care units.
- **Promising** because RIHAP has demonstrated that a TEOAE-based newborn hearing screening program can be used to screen every live birth and is very successful at identifying infants with hearing impairments.
- **Provocative** because the evaluation data raise many new questions about how to interpret TEOAE results, how to further refine the techniques, and how to best use the TEOAE method in conjunction with existing audiological measures.

As this issue of **Seminars in Hearing** goes to press, over 12,000 infants have been screened by RIHAP, and new information is continually being collected to improve the screening program. Plans have also been made to do a follow up of the first 3000 infants when they reach kindergarten. Such follow-up data will add even more to our knowledge about the validity of using TEOAE for newborn hearing screening.

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[1]It is important to note that screening and diagnosis have fundamentally different goals. The goal of screening is to select from the population, a smaller number of infants at highest risk of having a hearing loss. The goal of diagnosis is to confirm whether a hearing loss exists and describe the exact nature of that loss. Different techniques are used for diagnosis than for screening.

The purpose of this issue of **Seminars in Hearing** is to summarize the procedures and current results of RIHAP, and to discuss the implications from RIHAP for policy and practice related to neonatal hearing screening.

In the first article, **Historical, Political, and Technological Context Associated with Early Identification of Hearing Loss**, Mauk and Behrens summarize the historical context in which RIHAP was implemented.

In the second article, **Universal Newborn Hearing Screening Using Transient Evoked Otoacoustic Emissions: Results of the Rhode Island Hearing Assessment Project**, White, Vohr, and Behrens describe the design of the prospective clinical trial and summarize the data regarding the feasibility, validity, and cost efficiency of using the measurement of TEOAEs as a universal newborn hearing screening tool.

In the third article, **The Use of Transient Evoked Otoacoustic Emissions in Neonatal Hearing Screening Programs**, Kemp (the discoverer of otoacoustic emissions) and Ryan provide a basic summary of the nature of otoacoustic emissions, how they are measured, and why TEOAE is a particularly viable technique for newborn hearing screening.

The fourth article, **Operating a Hospital-Based Universal Newborn Hearing Screening Program Using Transient Evoked Otoacoustic Emissions**, provides a more detailed explanation of the day-to-day operation of RIHAP. This article, written by Johnson, Maxon, White, and Vohr, will be particularly useful for people considering the implementation of a TEOAE-based screening program.

Although TEOAEs can be objectively measured, many factors other than hearing sensitivity can affect the results. In the fifth article, **Factors Affecting the Interpretation of Transient Evoked Otoacoustic Emission Results in Neonatal Hearing Screening,** Vohr, White, Maxon, and Johnson summarize the factors which should be considered in the interpretation of TEOAE results.

Historically, newborn hearing screening programs have focused primarily on identifying infants with bilateral sensorineural hearing loss. One of the most interesting aspects about RIHAP is the emerging evidence, described by Maxon, White, Vohr, and Behrens in **The Feasibility of Identifying Risk for Conductive Hearing Loss in a Newborn Universal Hearing Screening Program**, that a TEOAE-based screening program may also be very useful in identifying infants at risk of persistent fluctuating conductive hearing losses.

To achieve its potential, a neonatal hearing screening program must function as one component in a system of services for young children with hearing disabilities. In the seventh article, **Intervention Issues Created by Successful Universal Newborn Screening**, Brackett, Maxon, and Blackwell discuss how services for young children with hearing disabilities must change to accommodate the substantially increased numbers of infants and toddlers identified by a successful neonatal hearing screening program, including those with conductive, mild bilateral sensorineural, or unilateral sensorineural hearing losses.

In the final article, **Implementing a Statewide System of Services for Infants and Toddlers with Hearing Disabilities**, Johnson, Mauk, Takekawa, Simon, Sia, and

Blackwell summarize the status of neonatal hearing screening programs in the U.S. and provide suggestions regarding the key issues that must be addressed in implementing a statewide program and service system.

Taken together, this series of articles provides the most comprehensive report to date of the Rhode Island Hearing Assessment Project. The results from this systematic evaluation of the TEOAE method as an universal newborn hearing screening technique provide convincing evidence that children with hearing disabilities can be identified early and that the goal of identifying all hearing-impaired children before 12 months of age by the year 2000 is achievable. RIHAP provides additional information upon which successful neonatal hearing screening programs can be built. It does not provide the final answers. Hopefully, the results of this project can be used by RIHAP and others to continue approaching the year 2000 goal of identifying all hearing impaired children before 12 months of age.

Much of the success of RIHAP can be attributed to the truly multidisciplinary nature of the staff and the unusual degree of interagency collaboration. The financial support, insightful technical assistance, and flexibility of the Office of Special Education Programs and the Bureau of Maternal and Child Health were instrumental in initiating the program and seeing it through to its successful conclusion. The leadership exhibited by Ms. Madeleine Will, Dr. Vince Hutchins, and Dr. Merle McPherson was particularly appreciated. Various state agencies in Rhode Island have also displayed an unusual degree of cooperation, support, and persistence in the achievement of this project. Drs. William Hollingshead and Peter Simon from the Rhode Island State Department of

Health; Dr. Peter Blackwell, Superintendent of the Rhode Island for the Deaf; Dr. William Oh, Chief of Pediatrics at Women and Infants Hospital of Rhode Island; and Dr. Barry Regan, Director of the Hearing and Speech Center at Rhode Island Hospital all contributed substantially to the success of the project. Expanding the project to Hawaii would not have been possible without the tireless work of Dr. Jean Johnson, Project Zero-to-Three Coordinator; Dr. Calvin Sia, past president of the Hawaii Chapter of the American Academy of Pediatrics; and Ms. Kitty O'Reilly, director of Rehabilitative Services at Kapiolani Medical Center for Women and Children. Biologic Corporation and Women and Infants Hospital of Rhode Island also made equipment available to the hospital that contributed greatly to the project's success. Finally, a number of consultants willingly contributed time and expertise, particularly during the early stages of the project. We are particularly grateful to Dr. David Kemp and Ms. Siobhan Ryan, University of London; Dr. Susan Norton, University of Washington; Dr. Don Morgan, University of Southern California; Dr. Charles Berlin, Louisiana State University; Dr. Harry Levitt, City University of New York; Dr. Jerry Northern, University of Colorado; Dr. James Jerger, Baylor University; and Dr. Maureen Hack, Rainbow Babies and Children's Hospital. Their insightful suggestions contributed much to the success of the project. However, RIHAP staff remain responsible for the design, execution, analysis, and interpretation of project results.

Finally, we express appreciation to the literally thousands of parents who were willing to accommodate a strict research protocol and the dozens of staff members who worked tirelessly (and frequently with insufficient rewards) to implement successfully the

research plan. What brings all these diverse people and agencies together is the common commitment to identify children with hearing impairments as early as possible and provide these children with the best possible services. It is to such children and their families that this special issue of **Seminars in Hearing** is dedicated.

Karl R. White, Ph.D.

Thomas R. Behrens, Ph.D.

Guest Editors

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Audiology Today, 1992, Vol. 4, No. 1, 16-17

Update

Editor's Note: Segments of this article were presented at a National Conference on Newborn Hearing Screening and Management in Houston, Texas. The Editorial Staff of ***Audiology Today*** *would like to thank Dr. Mahoney and colleagues for their willingness to publish their findings in the Bulletin.*

Utah Bureau of Communicative Disorders High Risk Registry Non-Respondent Survey

Thomas Mahoney
John Eichwald
Rebecca Fronberg

Over a thirteen year period, the parental response rate to the Utah High Risk Hearing Screening Program has averaged just over 50 percent. In an effort to improve future response rates, and to offer programmatic suggestions to other states just beginning to implement programs, a survey of non-responding parents was undertaken. Additionally, we wanted to know if infants of non-responding parents had risk profiles that were similar to the total high risk population.

The Utah Bureau of Communicative Disorders screens the birth certificate of nearly every live birth in the State for risk criteria associated with sensorineural hearing loss. From 1978 through 1990, 42,744 high risk notifications were mailed to parents, that informed them of their infant's risk status and offered them hearing screening without charge at various locations throughout the State. The notification packet contained an explanation of the program, a hearing development checklist, and a self-addressed, postage paid response card that noted the risk factor that put the baby at risk. Parents who did not respond to the first mailing were sent a second identical notice in two months, with an additional insert that restated their babies risk status.

The Survey

Out of 23,409 Utah live births between January and July 1990, 1,722 (7.4%) parents were sent high risk hearing notifications. Of 734 (45%) who did not respond, 106 were randomly selected to participate in a telephone survey conducted in April of 1991. The survey was designed to investigate potential reasons why parents did not respond to the Bureau's risk notification by returning the parental response card. Six questions were developed to accomplish this task. Three had a number of prompts that were asked when there was no self-generated response to the open ended inquiry. Of the 106 parents that could be contacted by phone, 103 were able to complete the phone survey, which took approximately five minutes.

A correlation of infant risk criteria was run between the 1,722 responding and 734 non-responding parents. A high correlation was found between the two ($r = 0.887$, $<1\%$), suggesting the risk factor(s) that placed a baby at risk did not effect the parents decision to respond to the program. Also, there was a high correlation ($r = 0.843$, $<1\%$), between infant risk factors in the surveyed group and the total pool of infants from non-responding parents. This indicates there was an appropriate sampling of the non-responding parents in the survey.

The following responses were obtained to the six survey questions:

Question #1:
"Do you recall receiving either of these cards?"

Ninety-five (92%) said yes, 8 (8%) said no. Those responding negatively received appropriate early identification information and were not subject to further questioning

Question #2:
"There are a number of reasons why people may not respond to a mailing such as this. Please tell me why you did not respond."

Seventy parents (74%) responded with only one reason, 25 (26%) had two reasons and 1 (1%) offered three reasons. Forty-seven (49%) responded by saying **there was nothing wrong with their child's hearing**. Forty-three of those responses were given freely, while four were the result of prompting. Twenty-three (24%) parents said they **forgot to return the card**, with only one prompted response, and 21 (22%) responded that they **have already had their child's hearing tested**. Eight (8%) indicated the **family history was not accurate**, 5 (5%) reported **doctor's advice** suggested not to respond, 3 (3%) said they were **concerned they may have to pay for testing** and one (1%) mother reported she **did not understand the card**. There were 16 **other** responses.

including 3 who were concerned about the **programs legitimacy**. The remaining 13 responses consisted of various reasons that could not be placed in specific categories.

Question #3:
"Did you talk to (Baby's name) doctor about this card?"

Eighty-two (86%) said no. 13 (14%) said yes. Those answering yes were asked:
"What did the doctor say?"

Seven (54%) parents reported that the doctor told them **not to worry about it**, with 4 of those answering without being prompted. Three parents (23%) said they were told to **return the card**, two (15%) physicians told the parents that the **child was not at risk**, and one ear, nose and throat specialist told one (1%) parent **I'll do the testing**.

Question #4:
"Did you understand why your child may have been high risk for hearing loss?"

Seventy-five (79%) parents answered yes, 20 (21%) said no. Those answering no were asked:
"Which high risk items did you not understand?"

Ten (50%) said they did not understand **Apgar score**, six of which had to be prompted into this response. Eight (40%) parents said, when prompted, that they did not understand **family history**. There were two responses (10%) to illnesses or condition of **pregnancy**, and one parent did not understand **asphyxia**.

Question #5:
"Do you remember reading the hearing checklist on the yellow card mailed with your notice?"

Sixty (63%) parents remembered the card and 35 (37%) did not. Those answering yes were asked:
"Did it influence your decision not to return the response card?"

Twenty-seven (45%) felt it did and 33 (55%) felt the checklist did not influence their decision not to return the card.

Question #6:
"Are you concerned about your child's hearing at the present time?"

Twenty (21%) parents reported yes they were concerned and 75 (79%) said no. Seventeen (85%) of the concerned parents arranged for a hearing test, and eight (11%) parents requested tests even though they were not concerned about their child's hearing.

Discussion:

Several response items deserve discussion. The statement that "nothing is wrong with my child's hearing", as a reason for not responding, probably reflects several programmatic issues. First, since the infants were about five months of age when the parents received the first mailing, they were probably exhibiting substantial auditory behavior at home. This could have affected a decision not to respond. Second, nearly half of the parents interviewed reported that the auditory checklist that was included in the packet influenced their decision not to respond. This finding addresses an important question of whether or not it is judicious to include information about normal auditory milestones in high risk mailers. This effort, while seemingly worthy, may serve to encourage inappropriate parental decisions regarding the need for audiological screening. The validity of parental observation and judgment about infant hearing development is an area that needs investigation.

We feel that many of the parents who reported they did not respond because they already had their child's hearing tested, had the screening as a result of receiving the risk notice from the State. It is probable that a number of these parents went to their infant's primary care provider, who subsequently referred them to other audiology resources.

It was interesting to find that 3% of the non-responding parents had concerns about the program's legitimacy. This suggests that parental notification by mail should be on official-looking letterhead, and although "warm and fuzzy" parental notices are intuitively attractive, they may conflict with the program's major goal.

The finding that only 14% of the non-responding parents said they talked to their baby's doctor "about the card" was somewhat surprising. It is felt that if the question was more generally phrased, more parents would have said they spoke to their infant's physician as a result of the risk notification. The importance of gaining the support of primary care physicians in implementing hearing screening cannot be overemphasized. Because of their increasing role as gatekeepers for total child health care, the primary care providers must become active members of the early identification team. Additionally, ongoing education of these providers is mandatory in successful hearing screening programs.

It is hoped that this paper is useful to those who are responsible for screening programs that depend upon parental responses. If further information is desired, please call (801) 584-8215. We would like to thank Dr. Karl White and Mr. Gary Mauk, of Utah State University, for their kind assistance in helping to develop the questionnaire portion of this survey.

Appendix C

Project Reference Bank

EARLY IDENTIFICATION

OF

HEARING-IMPAIRMENT IN CHILDREN PROJECT

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