

Early Hearing Detection and Intervention

History & Overview

It is estimated that three out of every 1000 children born each year in Oregon have a significant hearing loss (120-150 children). Fifty to sixty percent of these cases are believed to have a primary genetic cause. Studies have demonstrated that early detection of hearing loss in the first months of life and intervention prior to 6 months of age can result in significant benefits for the development of language and communication skills.

After several years of discussion and planning, mandatory newborn hearing screening was implemented in Oregon in July 2000 for all babies born in hospitals with more than 200 births per year. Several smaller hospitals also have chosen to provide this service. This accounts for over 90% of the children born in Oregon. With federal grants from the Maternal and Child Health Bureau within the Health Resources and Services Administration and the Centers for Disease Control and Prevention, Oregon has established the Early Hearing Detection and Intervention (EHDI) program within the Oregon Department of Human Services/Health Services, Office of Family Health.

Program Data

As of August 2002, forty-four hospitals in Oregon are providing hearing screening services for newborns; fifteen smaller hospitals and birthing centers do not provide these services, but are required by law to provide information to families about screening in other facilities. In Oregon, ten audiological facilities are capable of performing diagnostic hearing tests on newborns and young infants, and eight public and three private Early Intervention facilities provide services to children who are hard of hearing or deaf. A genetic evaluation for a child with hearing loss can be performed at two genetics clinics in Oregon, both in Portland.

In the first reporting year from July 1, 2000 to June 30, 2001, 42,826 screens were reported (91% of total births) including 1151 abnormal screens. Of those with abnormal screens, 970 children were referred to diagnostic centers, 397 diagnostic evaluations were performed, and eighty-seven children were identified with hearing loss. Only fifty-five children were enrolled in early intervention. The average age at enrollment was nine months.

Policy Development

Oregon's EHDI program receives guidance and input from the Newborn Hearing Screening Advisory Committee, a statutory committee that was established on passage of the newborn screening law in 1999. The committee includes medical professionals, audiologists, deaf individuals, and family members of deaf

individuals. The committee meets bi-monthly or monthly during legislative sessions.

Current policy efforts are geared toward pursuing legislation for mandatory reporting of individual level hearing screening, diagnostic, and intervention data to Department of Human Services/Health Services (DHS/HS) for the purposes of follow-up and program evaluation. A bill was introduced in the 2001 session, and while there was no vocal opposition, it died in committee due to other state priorities. Plans are in place to introduce similar legislation during the 2003 session.

Laws/Legislation

ORS 433.321 requires that all hospitals with greater than 200 births per year screen newborns for hearing loss within one month of the date of birth. All Oregon hospitals and birthing centers with less than 200 live births per year must provide the parent or guardian of a newborn child with the information concerning the importance of newborn hearing screening tests. Hospitals and birthing centers conducting newborn hearing screening tests must notify the parent/guardian and the health care provider for the newborn child of the test results, and must provide contact information for diagnostic facilities in the community. On an annual basis, hospitals must report to the department the number of children tested and the number of children with abnormal results. Early intervention facilities must, on an annual basis, inform the department of the number of children enrolled in the institution who have diagnosed hearing loss and who are receiving early intervention services. Parents have the option to dissent from testing for religious reasons and cannot be denied services due to inability to pay.

ORS 433.323 requires that the Department of Human Services collect information on newborn hearing screening tests from Oregon hospitals, birthing centers, and early intervention facilities and analyze the information to determine the effectiveness of the testing requirements in identifying hearing loss in the newborn child population. The department must issue an annual report detailing the results of the newborn hearing screening tests.

Data Collection, Analysis, and Utilization

The EHDI program is developing a data system that can be used to find and follow up on children who either did not receive screening or who did not receive needed diagnostic or intervention services. Currently Oregon law mandates reporting of annual aggregated newborn hearing screening data to DHS, which provides the EHDI program with some information for service planning and development. However, individual-level data on newborn hearing screening results, diagnostic testing results, and early intervention enrollments are necessary to ensure appropriate and timely follow-up services and to evaluate

and plan for hearing-loss related services. While a bill mandating collection of individual-level data was not passed during the 2001 legislative session, some screening, diagnostic, and early intervention centers are voluntarily submitting individual-level data to DHS.

In February 2002 the EHDI program launched a newborn data linking pilot study. The pilot study involves collection and linkage of newborn hearing screening, newborn metabolic screening, and birth certificate data from 3 hospitals. The linkage system uses the metabolic screening number as the unique identifier. When newborns are screened for hearing loss in one of the pilot hospitals, results are either sent electronically to DHS or entered on the infant's metabolic screening card to be submitted and processed by the Oregon State Public Health Laboratory. Plans are in place for the EHDI program, in collaboration with hospitals, diagnostic centers, early intervention facilities, local public health agencies, and health care providers, to coordinate the data and track newborn hearing follow-up to ensure that children and families receive the services they need and desire.

Quality Assurance

Hospitals, diagnostic centers, and early intervention facilities are responsible for maintaining the quality of their programs and services. The EHDI program is available to provide technical assistance and to conduct in-services as needed. The EHDI program tracks aggregate numbers of newborns screened, aggregate numbers of abnormal results, and aggregate numbers of infants enrolled in early intervention centers. The majority of hospitals, diagnostic centers, and early intervention centers also supply voluntary information such as the number of infants who received diagnostic testing, the number identified with hearing loss, and the number referred to early intervention.

Public and Health Care Provider Education

Efforts are underway to develop and disseminate educational materials and presentations for the general public and health care providers about the importance of newborn hearing screening and follow-up. Materials for expectant parents, prenatal care providers, and pediatric providers are being developed by the state EHDI program, as is a resource guide for families of children identified with hearing loss.¹ Information about newborn hearing screening is included in the "Newborn Handbook," a DHS publication given to all new parents through birthing hospitals or facilities.

¹ Final print versions available in November 2002