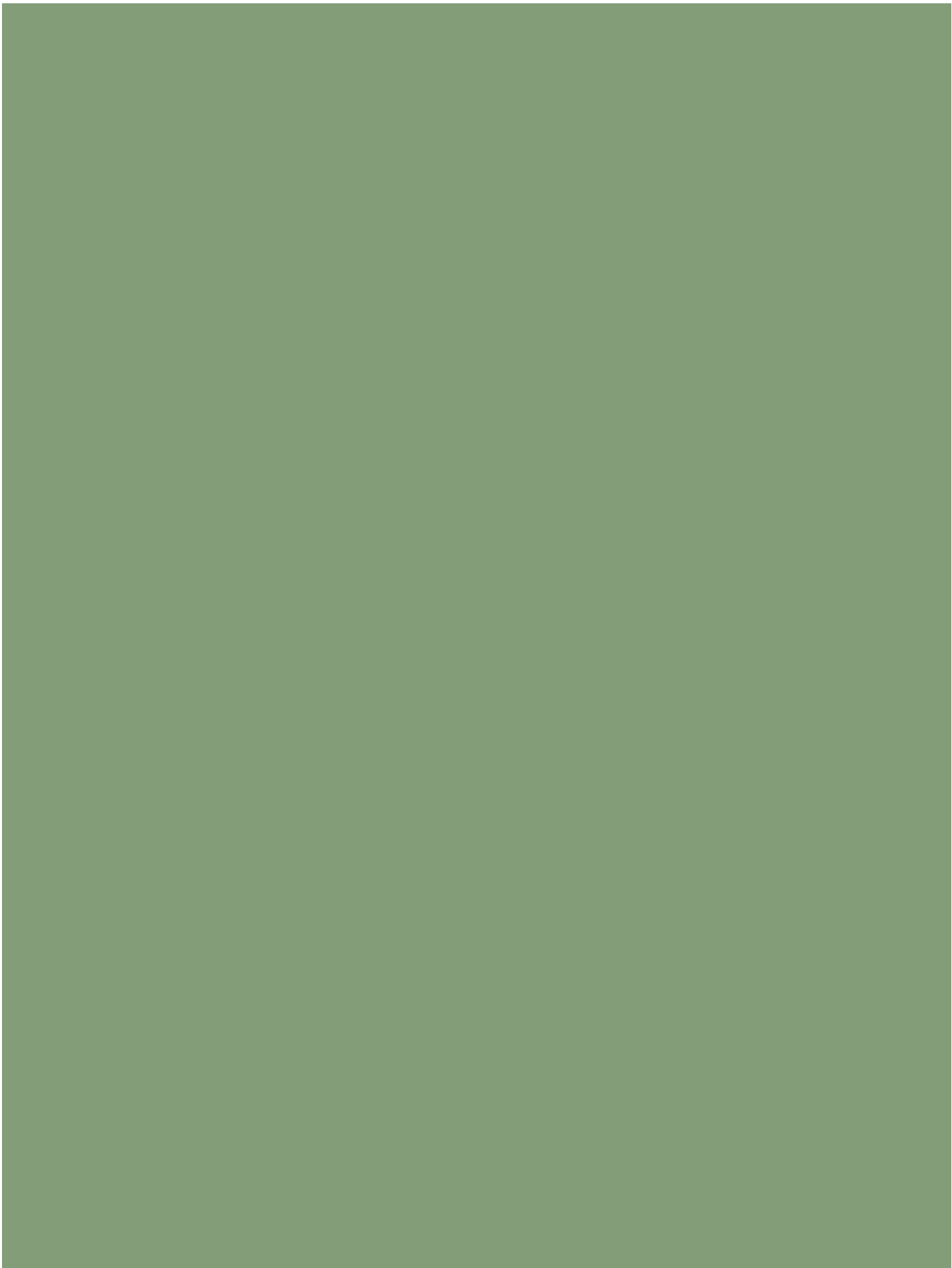


The Oregon Early Hearing Detection and Intervention (EHDI) Program



Oregon
Health
Authority

Annual Report 2013



Introduction



The Early Hearing Detection and Intervention (EHDI) program of the Oregon Health Authority collaborates with hospitals, audiologists, local public health departments, and early intervention programs to ensure that infants with hearing loss are identified early and receive appropriate and timely intervention services for optimal developmental outcomes. The goal of the EHDI program is to maximize linguistic competence and literacy development for children who are deaf or hard of hearing. EHDI strives to achieve that aim by assuring that all Oregon births achieve the national recommendation of:

- Universal hearing screening by 1 month of age
- Identification of hearing loss by 3 months of age for children who refer on screening
- Enrollment in Early Intervention by 6 months of age for children diagnosed with hearing loss

Current Oregon legislation mandates newborn hearing screening for infants born in hospitals with more than 200 births a year, and establishes an unfunded hearing screening registry, tracking, and recall system to ensure timely follow-up and intervention. In addition, the legislative mandate created the Newborn Hearing Screening Advisory Committee, a body of stakeholders that has met quarterly for over ten years to advise the EHDI Program on the implementation of the legislative mandate.

The EHDI program is funded through two federal grants from the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA). The CDC grant is focused on the development, maintenance and enhancement of the EHDI information systems and surveillance programs. The HRSA grant is focused on improving the number of children in Oregon who receive screening, diagnosis and early intervention services by the 1, 3, and 6 month milestones.

EHDI receives hospital newborn hearing screening results through the Oregon Vital Events Registry System (OVERS), which collects birth certificate data. Screenings that occur outside the birth hospital (e.g. for an infant screened at a screening clinic) and diagnostic follow-up evaluation data are recorded in a secure web-based data entry system. In addition, EHDI works closely with early intervention program partners to assure timely referrals upon diagnosis, and to receive information about the enrollment status of infants referred for early intervention services.

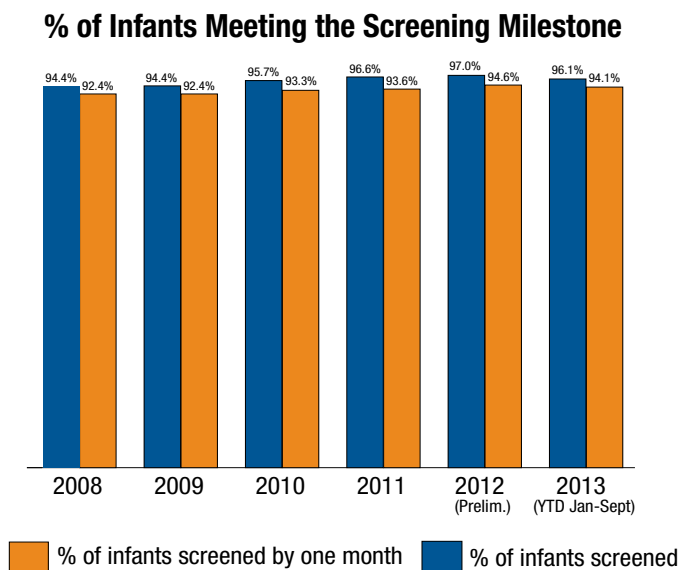
The Oregon EHDI program participates in the CDC national survey, providing annual data on the number of infants screened, diagnosed with hearing loss, and enrolled in early intervention each year.



"The success of EHDI programs depends on families working in partnership with professionals as a well-coordinated team."

Joint Committee on Infant Hearing (2007)

The EHDI program works to assure that all infants receive a hearing screening by one month of age. The total percentage of infants screened increased in 2008 and has increased slightly since then. The following graph shows the overall screening rates for the past six years.



Preliminary 2012 and year-to-date 2013 data shows that almost all infants born in mandated screening hospitals receive a hearing screening, and the vast majority of these screenings occur before one month of age. Infants born in mandated screening hospitals represented 93.7% of all Oregon births in 2013. Screening rates are lower for the remaining 6.3% of infants who are born in non-mandated hospitals or out-of-hospital settings. Screening rates are lowest for infants born at home. Screening rates increased across all birth facility categories between 2011 and 2012, with the largest increases seen in birth centers. Screening rates dropped slightly for all categories from 2012 to 2013.

| Type of Birth Facility (% of all births) | % of infants screened | | | % of infants screened by one month | | |
|---|-----------------------|-----------------------|------------------------|------------------------------------|-----------------------|------------------------|
| | 2011 | 2012 (preliminary) | 2013 (YTD Jan-Sept) | 2011 | 2012 (preliminary) | 2013 (YTD Jan-Sept) |
| Mandated screening hospital (93.7%) | 99.4% | 99.8% | 98.8% | 97.2% | 98.2% | 97.4% |
| Non-mandated hospital (2.7%) | 86.6% | 91.0% | 89.2% | 82.9% | 86.7% | 86.0% |
| Home birth (2.1%) | 26.3% | 27.1% | 25.0% | 9.6% | 10.3% | 12.2% |
| Birth center (1.4%) | 44.2% | 40.7% | 35.3% | 12.7% | 14.2% | 12.7% |
| All births | 96.6% | 97.0% | 96.1% | 93.6% | 94.6% | 94.1% |

Oregon EHDI staff are currently taking the following actions to increase hearing screening:

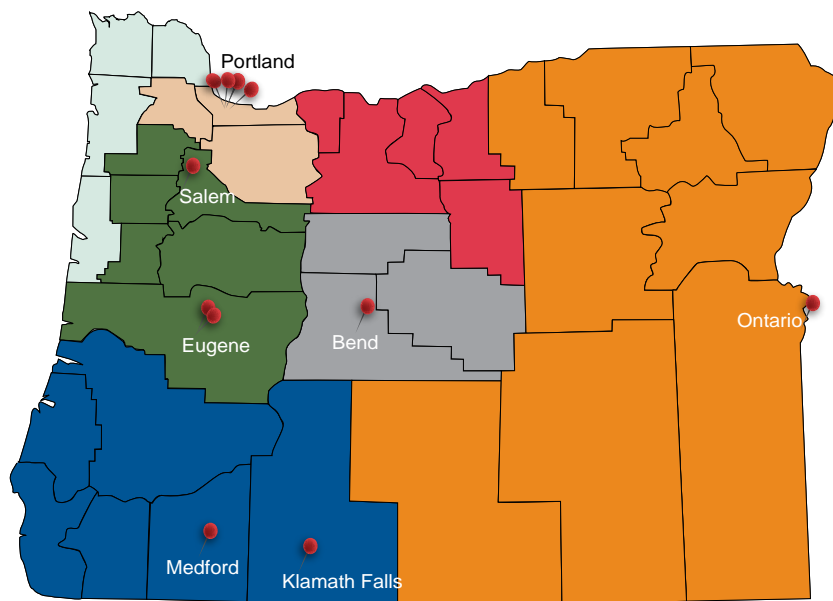
- Placement of hearing screening equipment for free screening clinics
- Working with midwives to increase knowledge of the importance of hearing screening
- Sending bilingual (English/Spanish) letters to families of children with incomplete screening results
- Sending letters and requests for information to providers of children at risk for loss to follow-up
- Use of key performance measures and report cards to support quality improvement by hospital screening programs

Diagnostic Audiology

While the vast majority of infants in Oregon do receive a newborn hearing screening, only a minority of infants needing a diagnostic evaluation are reported to have received it. The EHDI program's goal is that all infants who refer on the newborn hearing screening receive a diagnostic evaluation by three months of age. In 2012, preliminary data show that 1,231 of the 45,412 infants that were screened (2.7%) received a "refer" result. As seen in the following table, 53% of these referred infants had a documented diagnostic evaluation. Only 37% of these infants had a documented diagnostic evaluation by three months of age.

| Geographic region of birth | % of referred infants with documented diagnostic follow-up | |
|----------------------------|--|------------------|
| | 2011 | 2012 (prelim) |
| Portland Metro Area | 67.8% (301/444) | 65.3% (275/421) |
| Willamette Valley | 58.9% (206/350) | 61.1% (229/375) |
| Eastern Oregon | 48.1% (39/81) | 23.1% (45/195) |
| Coastal/NW Oregon | 60.0% (18/30) | 50.6% (41/81) |
| Southern Oregon | 30.8% (62/201) | 42.3% (47/111) |
| Central Oregon | 25.8% (23/89) | 35.3% (12/34) |
| North Central Oregon | 30.0% (6/20) | 14.3% (2/14) |
| ALL Oregon births | 53.9% (655/1215) | 52.9% (651/1231) |

The biggest differences in this milestone were regional: infants who live outside of the Portland metro and Willamette Valley areas are less likely to have documented diagnostic evaluations. As seen in the map to the right, diagnostic audiology facility locations are generally clustered along the I-5 corridor.



Oregon EHDI staff are currently taking the following actions to increase diagnostic follow-up:

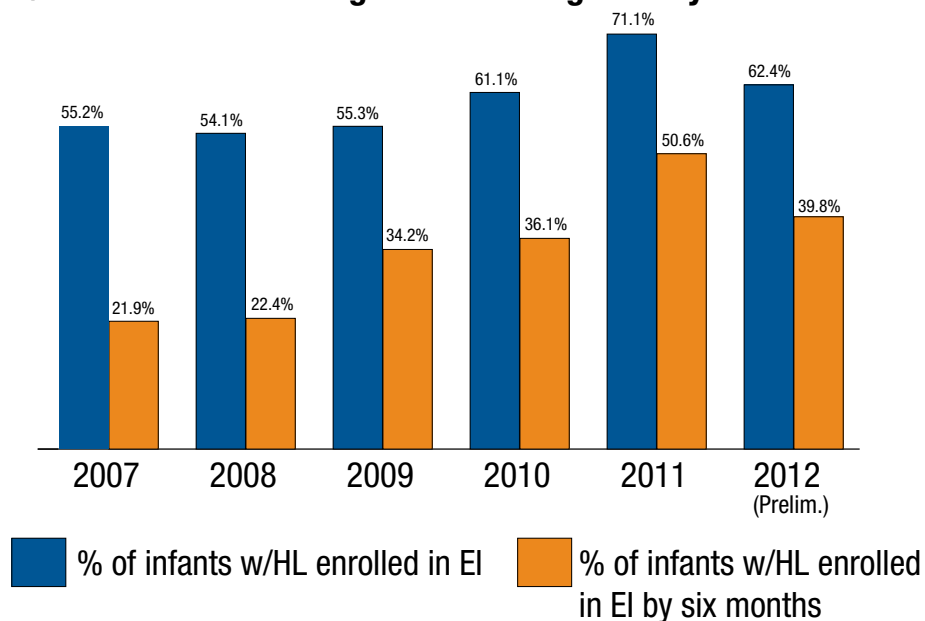
- Full implementation of a web-based audiology reporting system
- Participating in a national quality improvement project to reduce loss to follow-up after screening
- Utilizing an audiology consultant to support open communication and best practices with providers
- Placement of additional diagnostic equipment in locations with high loss to follow-up
- Sending bilingual (English/Spanish) letters to families of children at risk for loss to follow-up
- Sending letters and requests for information to providers of children at risk for loss to follow-up
- Providing publications and materials for families to help them understand the process
- Use of public health nurses in follow-up
- Use of Parent Guides in follow-up (see page 7: EHDI Partnerships)

Early Intervention

EHDI's goal is that all infants with confirmed hearing loss enroll in Early Intervention (EI) by six months of age. The percentage of infants with confirmed hearing loss who enroll in EI remained steady in 2007 through 2009, increased in 2010 and 2011, and decreased again in 2012 as seen in the graph below.



% of Infants w/Hearing Loss Enrolling in Early Intervention



Oregon EHDI staff are currently taking the following actions to increase EI enrollment:

- Continuing to have a Follow-up Specialist that communicates regularly with early intervention programs
- Working with Guide By Your Side and public health nurses (see next sections)
- Improvements in data sharing between early intervention and EHDI
- Full implementation of the automated direct referral process from audiologists to early intervention programs

EHDI Partnerships



In addition to hospitals, audiologists and early intervention programs, Oregon EHDI also partners with Oregon Hands & Voices to support parents of children newly diagnosed with hearing loss with trained peer mentors through the Guide By Your Side (GBYS) Program. In addition to providing information and support to families with newly diagnosed children who are deaf or hard of hearing, Guides work to reduce loss to follow-up by contacting families by phone to encourage them to return for additional needed diagnostic evaluation.

The EHDI program also partners with local public health nurses who serve as detectives and advocates to contact families of children who are at risk of not meeting the national 1-3-6 milestones, as well as to assure that children needing additional care coordination are connected with other programs, services, and resources such as CaCoon (Care Coordination for Children with Special Health Needs). Nurses receive direct referrals for those children needing follow-up and report outcomes which are recorded in the EHDI Information System.

Summary and Next Steps

Almost all infants born in Oregon receive a hearing screening, especially if born at a mandated screening hospital. The EHDI program is working to increase screening rates among infants born at non-mandated hospitals and out-of-hospital settings. Slightly more than half of all referred infants return for a diagnostic evaluation, and referred infants outside of the Portland metro area are less likely to have a diagnostic evaluation. Increasing the rate of diagnostic follow-up for referred infants is one of Oregon EHDI's most pressing priorities. Oregon has made great strides in improving the percentage of infants with confirmed permanent hearing loss who are enrolled in early intervention services, and we continue to dialogue with our early intervention partners about ways to streamline our referral and data sharing efforts. In addition to continuing our comprehensive efforts to improve screening, diagnostic evaluation and early intervention enrollment rates, Oregon EHDI is engaged in a number of other projects and initiatives, including:

- the National Initiative for Children's Healthcare Quality (NICHQ), Improving Hearing Screening and Intervention Systems (IHSIS) project,
- the CDC Sentinel Surveillance Project,
- the Public Health Data Standards Consortium EHDI CDA Pilot Project, and
- the National Early Childhood Assessment Project with the University of Colorado.



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