

EHDI team: Our team remains stable, with a few changes:

- Shelby Atwill, AuD, our new part-time audiologist, started with us on July 1st. Over the past three and a half months, some of Shelby's accomplishments include:
 - 1) Establishing a newborn screening program at Andaluz Waterbirth Center-Portland
 - 2) Updating the Oregon Newborn Hearing Screening protocol with progress toward creating definitive diagnostic and outpatient rescreening protocols
 - 3) Co-presenting Audiology 101 with Heather Durham to community health nurses, midwives, and other partners
 - 4) Adding 30+diagnostic records to EHDI-IS database (audiologist was needed to translate faxed documents lacking narrative reports)
 - 5) Developing a partnership with Pacific University audiology program through capstone project

- Sharon Coryell, our summer intern who developed, administered and analyzed the Parent Survey, will continue to work for EHDI this fall. She has been a fabulous addition to our team. She has also helped on other EHDI research projects:

Program funding details: EHDI is funded through grants from the CDC (\$162,365) and HRSA (\$279,000), with some in-kind staff time through the Title V MCH Block Grant. In general, the CDC grant is focused on the development, maintenance and enhancement of EHDI information systems and surveillance programs. CDC is highlighting the evaluation component of our grant this year so we will be looking at what additional evaluation processes need to be in place. The HRSA grant is focused on reducing loss to follow-up at the 1-3-6 milestones. This year's grant will also focus on the importance of using Quality Improvement (QI) methodology to continue to improve EHDI programs.

Our CDC progress report for July 2012-June 2013 was submitted on September 23, 2013. We received notification that we will continue to receive full funding from CDC again this coming year July 1, 2013-June 30, 2014 (\$162,365).

The HRSA Performance Report which requires EHDI to score the program on a series of performance measures is due December 6, 2013. All progress reports and any continuation application documents are available upon request.

CDC Site Visit: On July 29th and 30th we were fortunate to have the opportunity to host our leadership team from CDC. The CDC EHDI site visit team included our CDC Program Lead, Project Officer and their Evaluation Fellow. They reviewed our program, work plan, cooperative agreement, overviews of our information system, evaluation plan, a review of our participation in the CDA Pilot Project, a discussion of partnerships and collaborations, as well as our successes and challenges. A draft site visit findings should be available by early November.

CDC and HRSA Grant Objectives: The attached spreadsheet provides an integrated list of the proposed objectives for both the CDC and HRSA grants. The status column is updated to reflect the current state of each objective. Objectives have been modified in both the CDC and HRSA continuation applications to conform to federal requirements and/or to reflect the current status of the work and our expectation for completion. Most noticeably, with the 2013-2014 CDC continuation application, we were required to reframe our objectives more concretely with the intent of the funding opportunity announcement and focus of the CDC grant on the EHDI Information System (objectives in blue).

Advisory Committee membership: The 2012-2014 EHDI Advisory Committee term began at the June 2012 meeting. Pam Fortier is now Chair, and Anne Heassler is Vice-Chair for the current term.

EHDI Information System Updates: No major system enhancements were made this quarter.

EHDI Newsletter: Julie completed the Summer 2013 edition of the EHDI Newsletter and it was sent mid-August. Thanks to all who have offered story ideas and/or content. We are now posting the newsletters to our EHDI website. The current edition as well as previous editions may be found on the EHDI website. We are planning our next issue for Winter 2014, to be distributed in mid-February. We are always looking for ideas for upcoming issues - please send your suggestions to: julie.a.hass@state.or.us.

OREGON EHDI Website: The Oregon EHDI Program was honored this year by winning the 2013 Website of the Year award presented at the Twelfth Annual Early Hearing Detection and Intervention meeting in Glendale, Arizona, in April 2013. The EHDI Team acknowledges Britt Parrott's fabulous work as our website coordinator.

Guide By Your Side Update: We have five parent guides. Currently we have openings in Southern and Eastern Oregon. Our Lane County and Central Oregon guides are fully trained and working with families. They each have a mentor in two of our more established parent guides. The mentors connect with the new guides weekly and ensure they understand their role as guides.

The Guide By Your Side Program Coordinator has been working on getting training for the guides on topics that include the difference between Post Partum Depression, baby blues and grief, and we have partnered with Oregon Family to Family to provide a webinar on how to navigate the insurance company.

Two of the parent guides attended the Audiology 101 webinar last month, one attended a conference call on Bullying, Abuse and Neglect and two are attending the HEART conference later this month. Otherwise it has been business as usual for the guides!

Partner Training and Professional Development:

Hospital Screening Partners: In the past three years, 79% of our screening hospitals have been represented at either an in-person or webinar training. Among our screening hospitals, there are 8 which have not participated in training in the past 3 years. These hospitals, concentrated in the Central and Coastal parts of the state, are slated to receive site visits over the remainder of 2013. On October 3rd and 4th, Shelby Atwill, Meuy Swafford and Heather Durham visited 3 screening hospitals (St. Charles Hospital in Bend, Redmond, and Madras), 2 audiology centers (Pacific Northwest Audiology and Central Oregon Ear Nose and Throat) and trained a number of midwives on screening newborns with an OAE and implementing a free screening program. Overall the visits went well. The team will summarize the findings and make recommendations to the individual sites.

Audiologists: Oregon EHDI has been partnering with the Oregon Academy of Audiology (OAA) to support the inclusion of pediatric content at annual OAA conferences, and to make Oregon EHDI information and materials available to attendees. EHDI Follow-up Specialist and Audiologist, Julie Hass and Shelby Atwill, were asked to provide a brief overview of required diagnostic reporting at the OAA Fall Conference on October 26. Two audiology facilities were also visited during the recent Central Oregon site visit.

Pediatricians and other medical providers: Before retiring from the Committee, Dolores encouraged us to piggyback on Dr. Tharpe's trip to Oregon by inviting her to speak at a pediatric grand rounds at Oregon Health & Sciences University. With the support of our OHSU Advisory Committee members, Dr. Tharpe spoke to residents and other hospital personnel on Friday, April 26.

Public Health Nurses and other Screening and Follow-up Partners: EHDI Audiologist, Shelby Atwill and audiologist partner Heather Durham, co-presented a 90-minute Audiology 101 webinar on September 10. This webinar offered public health nurses, midwives, and other screening partners a foundation of audiology information to support their screening and follow-up activities with families. Forty people attended, with 70 registered, and generated excellent feedback. The webinar was recorded and distributed to those registered, and has been posted to the Oregon EHDI website. It is planned to distribute the recording to additional partners and interested entities.

A panel of EHDI staff, partners, and Advisory Committee members will be presenting on the continuum of the EHDI system at the Midwives Alliance North America (MANA) conference on October 27th in Portland. This conference draws upwards of 350-400 midwives from across the country and is expected to have a strong attendance by Oregon midwives. Special thanks to Caroline Peterson for encouraging us to submit an abstract for participation.

Partner Performance Reports:

Hospital Screening: We have been providing quality assurance reports for hospital newborn hearing screening program staff through a secure online web portal since October 2010. These reports are available on-demand, and the user may select the date range of interest. Available reports include both aggregated summary data for each hospital's birth, with summary indicators for diagnostic evaluation and EI enrollment, when data is available, as well as a child-by-child line report of each case with respective hearing screening outcomes. The intent is that hospital hearing screening staff will use the reports to monitor their status on a weekly basis, as well as use the indicators to identify areas for improvement to meet the national goals for screening, screening by 1 month of age, and maintaining a low refer rate.

Audiologists: No update to report. We are creating a comparable quality assurance report for diagnostic audiology centers. Like the hospital reports, these will include both summary and individual data that reflect the efforts of audiologists to perform follow-up for children who referred on newborn screening. In addition, these reports will provide audiologists with information about their contribution to the overall number of referred infants in their region or catchment area needing diagnostic follow-up services. A draft audiology report card has been shared with a small group of stakeholders for feedback.

Loaner equipment update: Since the July update, Oregon EHDI has placed OAE equipment at one midwife birthing center: Andaluz Waterbirth Center in Portland. Andaluz began offering newborn hearing screenings for their clients in early August and has since screened seventeen babies. Discussion of placement of additional loaner OAE equipment is underway at Peace Harbor Hospital, Peace Health Midwifery, and Douglas County. Selection of these facilities was based on need, region, population served, and interest/ability to provide service. Following agreement of all loaner terms, EHDI audiologist will provide in-person training on screening and communication. Placement of the two pieces of A-ABR equipment purchased in June 2013 is pending, with three existing pieces of OAE equipment yet to be placed.

Audiology Data Audits: No update to report. We continue to work to reduce our high loss to follow-up rate by inviting selected audiology providers to participate in data audits. Regional and facility-specific lists are generated of children who referred on newborn hearing screening but for whom we have no diagnostic evaluation results. We request that providers review lists of children from their facility or region who meet these criteria and identify if they have seen any of the children but neglected to report results. Among these selected audiology audit snapshots, we have seen between 15-54% underreporting.

Early Intervention Pilot: The EHDI direct audiologist to EI referral and reporting pilot process is going well. This process allows audiologists to refer children diagnosed with hearing loss directly to the appropriate EI Program through our data system at the time of reporting. Our system documents the referral details, and an automated report monitors the receipt of the

referral. With three simple steps, EI Program staff can enable data sharing of eligibility and enrollment outcomes from ecWeb: 1) enter EHDI as referral source in ecWeb, 2) obtain and record parent consent in ecWeb, and 3) enter child ID in EHDI-IS. We currently have 5 active pilot sites, and are scheduled to train Multnomah EI. At last analysis, the automated referral process accounts for 41% of referrals being sent, and significantly reduces the burden on our Follow Up Specialist to send, track, and follow-up on nonresponsive EI programs.

Early Intervention Data: We have requested that all EI Providers indicate EHDI as a referral source and obtain and indicate consent to share data for all referred children and those who are being considered for hearing impairment eligibility, regardless of referral source, in ecWeb. These simple steps enable data sharing and reduce the burdensome process of reporting outcomes by phone or fax. As of August 2013, as shown in Table 2 below, for referrals sent in January 2012- June 2013, EHDI received eligibility and enrollment data through ecWeb for 63% of referred infants. EHDI received eligibility and enrollment status for another 21% of infants referred in January 2012- June 2013 by fax or phone notification

These statistics reinforce several ongoing pieces of work with our EI partners: 1) to support EI providers in routinely obtaining consent and indicating EHDI as a referral source in their data system; 2) to support the remaining EI programs not currently participating in the direct audiologist to EI referral process in joining, and 3) to work with audiologists and EI providers to assure reporting on all children being evaluated for hearing impairment, whether initially referred through EHDI or not.

Table 2: Status of EI Reporting for EHDI Referrals Sent from January 2012-June 2013, (analyzed 8/21/2013)

	# (% of total) referred by EHDI with eligibility and enrollment data received through ecWeb	# (% of total) referred by EHDI with eligibility and enrollment data received via fax/phone	# (% of total) referred by EHDI, no information received back	Total # referrals
Totals:	148 (63%)	50 (21%)	38 (16%)	236

*Analysis is available by Service Area upon request.

OTHER PROJECTS:

EHDI Interoperability using Clinical Document Architecture (CDA) Standard: Oregon EHDI successfully completed our participation in the Clinical Document Architecture (CDA)

pilot project with the CDC to demonstrate electronic data exchange between clinical Electronic Health Record (EHR) Systems and public health EHDI information systems using Health Level Seven (HL7) standards. Our team demonstrated the feasibility of receiving a well-formed, valid CDA Newborn Hearing Screening Outcome Report and parsing the data into our EHDI-IS. The other pilot state, North Dakota, demonstrated sending a newborn's demographic and hearing screening results to the ND EHDI-IS where an Early Hearing Care Plan CDA document was created and sent to a nurse provider who was then able to access and read the report.

The Oregon EHDI team overcame multiple challenges to successfully complete our portion of the pilot project and was instrumental in identifying key elements for a readiness assessment for other states to use in determining capacity and resources to participate in projects like this in the future.

Special thanks to Denise Kossover-Wechter and Heather Durham for encouraging their IT staff to participate as observers in this pilot! And, a special commendation to the MCH Informatics team and Meuy Swafford for finding a way forward with our designated task given all the obstacles.

National Initiative for Children's Healthcare Quality (NICHQ) Learning Collaborative:

Oregon was one of 17 states and territories participating in the cohort of the Improving Hearing Screening and Intervention Systems (IHSIS) learning collaborative from July 2012- September 2013. The learning collaborative entails monthly conference calls, and periodic in-person sessions that enable us to work with NICHQ team and other state EHDI programs to test, share and implement ideas to improve the quality and timeliness of screening, diagnostic evaluation, and entry into early intervention services. The project uses learning collaboration and quality improvement approaches. The NICHQ learning collaborative ended on September 17, 2013, and although it has ended, EHDI will continue to apply the learning in our future work.

CDC Sentinel Surveillance Project: Oregon continues to participate in the (unfunded) CDC Sentinel Surveillance Project. This project seeks to support continuous data quality improvement, and assure more timely assessment of loss to follow-up and loss to documentation among a representative group of states. Participating states were asked to provide a limited subset of the annual CDC data reporting elements for several quarters. An update is requested for each quarter to examine outcomes for children over time.

NECAP: Oregon Hands & Voices is partnering with Early Intervention staff across the state to collect standardized language assessments from parents of children diagnosed with hearing loss. Guides and EI providers are delivering assessments to families in the Metro, Southern Oregon, Salem, Eugene, and Central Oregon regions. To date, 88 families have been invited to participate, and 7 families have completed the assessments for scoring by the research staff in Colorado. Once the assessments are scored, the data will be entered into our EHDI-IS for use by

Early Intervention providers. We are planning to explore why the response to this opportunity has been so limited, in hopes to engage more families as the project continues.

EHDI Parent Survey: We are thrilled to have a PSU public health undergraduate student intern, Sharon Coryell, working with us on the EHDI Parent Survey. The Early Hearing Detection and Intervention (EHDI) program implemented a small-scale survey designed to evaluate the Oregon's Early Intervention (EI) program satisfaction of families whose children were diagnosed with hearing loss and are/were participating in early intervention.

The main purpose of the survey was to:

- Explore the type and extent of information and services that children with hearing loss and their families receive from Oregon's EI program
- Assess families' satisfaction with EI program services.
- Generate discussions and ideas to enhance the current survey methods of EI and EHDI programs.

This survey was conducted using SurveyMonkey and was open from July 1, 2013 to September 30, 2013. A total of 77 respondents completed the survey.

- The survey found that the Oregon Early Intervention program had many strengths. On average respondents reported "yes, very well" when asked "Do you feel that your early intervention program is providing services that will help your child successfully communicate", although some reported that more visits with EI services was needed/wanted.
- Several barriers to parents in receiving early intervention services were identified, including delays in being contacts, transportation challenges, difficulties scheduling appointments, and lack of child care.
- Over 77% of respondents reported that they were "very satisfied" with communication about the care their child is receiving between doctor and other health care providers.
- Over 21% of respondents reported there having been problems with health insurance not paying for services or equipment that was needed for the child.
- Over 88% reported having talked with an Early Intervention Specialist about their child's hearing.

EHDI Information System User and Quality Assurance Report Surveys: This fall, we will conduct a survey of EHDI Information System users to get an understanding of how satisfied users are of various aspects of the data system. This survey will also provide information about the types of training users have received and what additional training they would like.

We will also survey users of the hospital Quality Assurance Reports to get a sense of who is using those reports, how often they are accessed, and what additional information users would like to see in those reports.