

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

- Sharon Coryell, our summer intern who developed, administered and analyzed the Parent Survey, will continue to work part-time for EHDI this winter in an administrative support capacity. She has been a fabulous addition to our team.
- Sarah Hargand is joining us as research analyst. She holds a Master of Public Health degree in epidemiology and biostatistics from the Oregon Health Sciences University. She has worked for the State of Oregon's Public Health Division since 2010. She served as the lead research analyst for the Natality Team in the Center for Health Statistics, and currently works as an evaluator in the Maternal and Child Health section.

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, with a keen focus on using evaluation for program improvement. 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.

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 and report financials was submitted prior to the December 6, 2013 due date. Improvements in our performance measures include:

- Family members are offered training, mentoring and opportunities to lead.
- The grantee has assisted practice sites in implementing health information technologies in support of the medical home (PCP).
- Staff reflects cultural and linguistic diversity of the significant populations served and participate in professional development activities to promote their cultural and linguistic competence.
- Improvements in collaboration with other agencies and organizations in the formulation of coordinated policies, standards, data collection and analysis, financing of services, and program monitoring to assume comprehensive, coordinated services.

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. Oregon EHDI received the CDC site visit report at the end of October. Copies of the report are available at this meeting. The report highlighted accomplishments and challenges.

Accomplishments included:

- Moving to EHDI-IS has allowed for more accuracy, efficiency, and financial sustainability.
- Import from Immunization data provided PCP information for referred or unscreened infants.
- EHDI and Immunization are working towards a two-way data exchange intended to facilitate routing updates of the PCP to use for follow-up and real-time updates of every child's hearing screening and diagnostic results.

- Oregon EHDI successfully participated in a Clinical Document Architectural Pilot to demonstrate the feasibility of electronic data exchange between Electronic Health Records systems and public health EHDI-IS using Health Level Seven (HL7) standards.
- EHDI has also piloted an automated direct referral process to EI programs which allows EHDI to now have access to eligibility and enrollment data for approximately 93% of referrals to EI.

Challenges included:

- Some EI coordinators are not reporting EI data to EHDI due to lack of parental consent or FERPA.
- Collecting hearing screening data from midwives continues to be a challenge.
- Engaging family partners in rural areas has been difficult and a third of lost to follow-up children are in rural areas.

CDC and HRSA Grant Objectives: 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 notably, 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.

Advisory Committee membership: Pam Fortier is now Chair, and Anne Heassler is Vice-Chair for the current term. The EHDI team updated the membership roster in November 2013 for a possible discussion at the next Advisory Committee meeting. Claudia Meyer has been invited to serve as the Portland State University representative for the EHDI Advisory Committee. Claudia is a speech-language pathologist and director of the PSU Speech and Hearing Clinic.

EHDI Information System Updates: This quarter we added an ENT/physician field to the “Recommendations” section of the Diagnostic tab.

EHDI Newsletter: 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.

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. Each new guide is mentored by one 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.

Guides completed their self-evaluations in early December. The team will finalize our goals for the new year in early January. Some of the areas the team would like to focus on include: creating family events for Hispanic families, attending pre-natal classes at Andaluz Waterbirth Center and Alma to discuss with parents the importance of the newborn hearing screen. Individual Guides have also discussed ways in which to deepen their relationships with professionals in their community.

Partner Training and Professional Development:

Hospital Screening Partners: Among our screening hospitals, there are 11 that have not participated in training in the past 3 years, as of February 2013. These hospitals, concentrated in the Central, Coastal and Eastern parts of the state, are slated to receive site visits during 2013 and early 2014. Three Central Oregon screening hospitals (St. Charles Hospitals in Bend, Redmond, and Madras) were visited in October 2013. On November 21 and 22, Sarah Hargand and Meuy Swafford visited three screening hospitals in the Coastal region (Samaritan Pacific Communities, Samaritan North Lincoln, and Tillamook Regional Medical Center). Overall, the visits went well. The team will summarize the findings and make recommendations to the individual sites. Site visits to the remaining four hospitals, located in Eastern Oregon, are anticipated for early 2014.

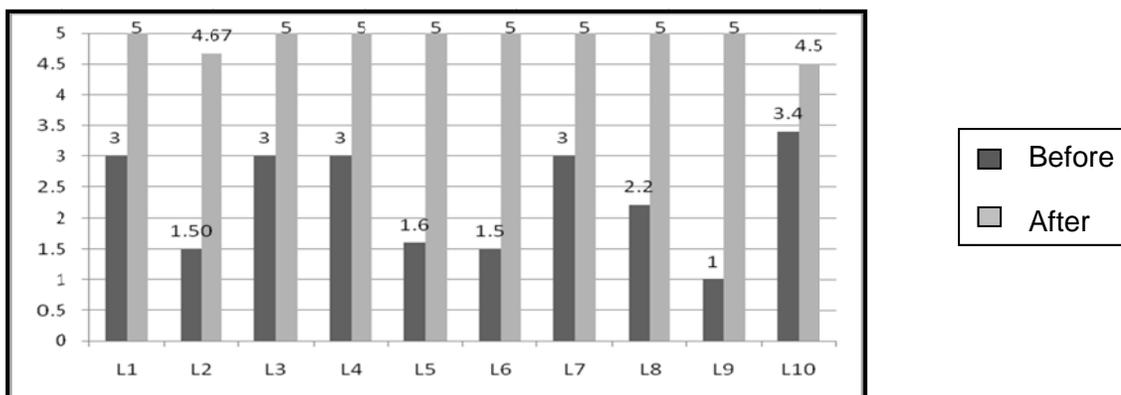
Audiologists: EHDI Follow-up Specialist and Audiologist, Julie Hass and Shelby Atwill, provided a brief overview of required diagnostic reporting at the OAA Fall Conference on October 26. This presentation generated the creation of several EHDI-IS accounts, interest in the requirements, and the development of a reporting policy. As part of our annual requirements, the audiologists currently on EHDI’s lists of approved facilities were contacted to ensure their information was current. Additionally, all audiologists who did not participate in the 2012 Audiology Census Survey were re-surveyed, and 11 additional pediatric audiology facilities were identified.

Public Health Nurses and Other Screening and Follow-up Partners: A panel of EHDI staff, partners, and Advisory Committee members presented on the continuum of the EHDI system at the Midwives Alliance North America (MANA) conference on October 27 in Portland. The presentation was recorded and is available through a password-protected link to all attendees. EHDI received the following feedback about the presentation:

Learning Objectives:

Participants will understand and be able to explain...

- L1: What the Early Hearing Detection and Intervention (EHDI) program is
- L2: The national milestones for hearing screening, diagnosis and intervention
- L3: The benefits of newborn hearing screening and early intervention
- L4: The rationale for screening for hearing at birth
- L5: The parent’s perspective of screening/having a child with hearing loss
- L6: The basic biological processes of hearing and hearing loss
- L7: The procedures and process of newborn hearing screening
- L8: The technologies available for children diagnosed with hearing loss
- L9: The characteristics of quality early intervention programs
- L10: The midwife’s role in early hearing detection and intervention



As a result of our participation in the MANA conference, EHDI was invited to present a similar panel at the Naturopathic Midwives Conference in April 2014.

Plans to begin a monthly free screening clinic at PSU are underway with the first clinic occurring on January 23. Families of infants born three months prior to the clinic date with (a) no documented screening or (b) still requiring follow-up were sent flyers about the clinic and how to schedule an appointment. This clinic is also available to families who are uninsured and contact the EHDI program. For the time being, unassigned EHDI loaner equipment will be used to support this monthly clinic.

Pediatricians and Other Medical Providers: MSR West has agreed to include EHDI brochures requesting purchasers of newborn hearing screening equipment to register with EHDI, as physicians are mandated reporters of hearing screening and diagnostic testing performed on children under 3 years of age. If this is a successful mechanism for identifying these physicians, we will reach out to the equipment manufacturers to request a similar dissemination of EHDI information.

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 births, 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.

Loaner equipment update: Since the October update, Oregon EHDI has placed OAE equipment at Bella Vie Gentle Birth in Salem. Bella Vie eagerly began offering newborn hearing screenings for their clients in early December and has since screened 12 babies. They will be expanding their services to include community members who have not received a screening starting in January.

Discussion of placement of additional loaner OAE equipment is underway at Peace Health Midwifery (Springfield) and with Public Health Nurses in 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, the EHDI audiologist will provide in-person training on screening and providing appropriate informational support for families. Placement of the two pieces of AABR equipment purchased in June 2013 is pending, with three existing pieces of OAE equipment yet to be placed. Unassigned loaner equipment may be used for demonstration during trainings, as loaners for equipment sent in for repair, or for the PSU free screening clinic.

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 6 active pilot sites.

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 December 20, 2013, as shown in Table 2 below, for referrals sent in January 2012- September 2013, EHDI received eligibility and enrollment data through ecWeb for 64% of referred infants. EHDI received eligibility and enrollment status for another 21% of infants referred in January 2012- September 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-September 2013, (analyzed 12/20/2013)

	# (% 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:	166 (64%)	55 (21%)	38 (15%)	259

*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 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.

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. NECAP will begin again in January 2014.

EHDI Information System User and Quality Assurance Report Surveys: Last fall, we conducted a survey of EHDI Information System users to get an understanding of how satisfied users are with various aspects of the data system. There were 21 EHDI users who responded to the survey. The majority of respondents were audiologists and most had been using the EHDI Information System for over one year. Most respondents were very satisfied with the accessibility and ease of entering data in the EHDI Information System and satisfied with the ease of navigation and tab organization. The majority of respondents also felt that the amount of data they were required to enter into the EHDI Information System was appropriate. We are also continuing to 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.