

EHDI team: No changes to team composition.

Program funding details: We were recently awarded short term funding from the Public Health Informatics Institute (PHII) to conduct Phase 2 of the EHDI CDA Pilot Project (more details later in the document) in partnership with Oregon Health & Sciences University (OHSU).

We submitted a non-competing continuation application to one of our federal funders, Health Resources and Services Administration (HRSA), in November 2014 for the grant period April 2015-March 2016, as well as two performance reports for prior budget periods.

As part of the modified reporting protocol for the Centers for Disease Control and Prevention (CDC), we have been working on a required logic model illustrating the inputs, activities, outputs, short, mid and long term outcomes of our EHDI Information System, as well as a summary of changes made in our Information System, including data elements, processes and features.

All reports, application documents and grant materials are available upon request.

EHDI Information System:

EHDI Information Exchange with Hospitals for Screening Data: Oregon EHDI and MCH Informatics team members have been working assiduously on Phase Two of the Clinical Document Architecture (CDA) pilot project in partnership with CDC and the Public Health Informatics Institute. Phase One demonstrated the feasibility of receiving a well-formed, valid CDA Newborn Hearing Screening Outcome Report and parsing the data into our EHDI-IS. In Phase Two, we are performing an exchange with real data (!!)- receiving and consuming newborn hearing screening results from OHSU's Epic system sent via HL7 into a Hearing Plan of Care (HpoC) document to be received and parsed into our Information System. Direct data exchange with hospital screening partners has the potential to eliminate duplicative data entry, thus improving efficiency of hospital staff, and assure more timely and accurate results for EHDI to use in our follow-up activities.

The team has been hard at work performing extensive data cleaning for our 2013 CDC Survey submission. Reviews included:

- Unusual screening+dx+EI patterns for incomplete processes and correction of collected information
- Each HL case to assure they followed the process from referred screening through to EI enrollment
- Every "in process" case to ensure data entry was complete
- Cases for screening/diagnosis entries placed in the wrong tabs and modified
- Last hurrah OOH and LFU mailings to improve screening and follow-up rates, detect any lingering LTD
- Sent lists of all 2013 LFU babies to key audiologic providers to detect LTD (thank you!)

Trainings and Technical Assistance:

Maternal and Child Health Nurse Orientation in October 2014: Our team provided an overview of EHDI and GBYS for new public health nursing staff working at local public health departments, specifically those nurses who perform home visiting, case management for children with special health needs, and other MCH services for families. From an EHDI perspective, these are the local public health nurses who receive our referrals for

children diagnosed with hearing loss, as well as referrals to assist in supporting families through diagnostic follow-up.

EHDI Information System Refresher in December 2014: We hosted a webinar for audiologists and other EHDI reporters focused on improving data reporting consistency and quality. The team offered an overview of the EHDI program, EHDI law, sources of EHDI data, end users of EHDI data, reporting protocol, a system demonstration, discussed common errors in reporting, and described loss to follow-up and loss to documentation. The webinar was recorded and will be available for viewing at our website:

<http://healthoregon.org/ehdi>

Out of Hospital Birth Updates:

We are holding steady with hearing screening equipment placed at 7 midwifery practices (including 6 of the 10 birth centers with the highest birth counts). In addition to offering screenings for their own births, most also offer screening for community members through regular screening clinic dates or by appointment. In addition, Shelby has been working with several of these providers to implement bachelor’s level screening interns to help assure sufficient capacity to meet the need.

Midwifery Screening Partners	Reported Birth Count, 2014	Own births screened*, count (%) 2014	Total screens documented to have been performed by screening site, 2014
Alma Midwifery (Portland) [screening since 1/2013]	89	57 (64%)	176
Andaluz Waterbirth (Portland and Tualatin) [screening since 8/2013]	149	107 (72%)	164
Bella Vie Gentle Birth (Salem) [screening since 12/2013]	74	60 (81%)	93
Canyon Medical Center (Portland) [screening since 9/2014]	36	19 (53%)^	9
Growing Family Birth Center (Lebanon) [screening since 2011]	33	29 (88%)	51
PeaceHealth Nurse Midwifery (Eugene) [screening since 5/2014]	147	109 (74%)^	45
Trillium Waterbirth/WiseWoman Care (Medford) [screening since 7/2014]	53	21 (40%)^	18

*Birth facility may not have been the screening facility.

^Sites began screening in 2014. Start dates are noted. % screened is portion of total annual birth count.

Loss to Follow-Up:

HRSA-funded EHDI Programs are expected to achieve annual 5% improvements in our diagnostic follow-up rate.

Oregon EHDI's follow-up protocol includes:

Weekly:

- Letters to families of unscreened and referred infants
- Letters and fax back forms to primary care providers of unscreened and referred infants
- Phone calls to families of infants at risk of LFU approximately 2 weeks to one month after letters are mailed (by Parent Guide)

Monthly:

- Requests for information (RFIs) to the Newborn Hearing Screening Coordinator at hospitals for confirmation and updates to data for any infant with missing, incomplete or refer results in OVERS.
- Rolling loss to follow-up audit lists to voluntary participating audiologists to review and identify any infants evaluated but not yet reported in EHDI-IS.
- In-process and Hearing Loss audit list to diagnosing audiologists requesting status updates to records.
- Referrals of infants diagnosed with HL to EI at approx 6 mos of age if not already referred by diagnosing audiologist.
- Letters to families and PCPs of in-process infants with lists of resources and audiologists to support completion of diagnosis.
- Letters to families of HL babies not previously referred to EI by audiologist.

Periodic/On-going:

- Brief family questionnaire to parents of unscreened and referred/no follow up infants.
- Extensive custom follow-up activities for infants needing medical evaluation
- Public health nursing follow-up
- Extensive use of monitoring reports
- Technical assistance to partners

Audiology Updates:

Oregon EHDI just received the summary findings of NCHAM's 2014 Audiologist Practices survey examining parent hearing aid education and support. Oregon EHDI provided the names and mailing addresses of our pediatric audiologists and mailed the surveys, prepared by NCHAM. NCHAM analyzed the data and provided a summary of findings for the nation and our state. Generally, Oregon pediatric audiologists perform as well or better than the national average. Some of the areas indicate additional training is desired/needed, so these results will be used to inform future webinars/trainings. The report is available for review.

We started to send monthly data reports to each audiology practice that has any active/in-process babies and/or babies who have a degree of hearing loss or diagnosis but who have not yet been referred to EI. The report includes the last reported diagnostic information. Audiologists are asked to review the report and provide any missing information (future appointment dates, missing results, no-show/re-scheduled appointments, status updates, communications with the family, etc.) in the data system. This information, updated monthly on all the "active" cases in our system, is helping our team a) be more efficient in our follow-up activities, b) refer some of these babies on to EI in a timely manner, and c) helping support audiologists in their reporting and data system navigation practices.

Early Intervention Updates:

Beginning with the 2013 data, the CDC is requesting the initial IFSP date for each child referred to Early Intervention (EI) for hearing loss to represent the date of enrollment into Early Intervention.

Individual Family Service Plans (IFSPs) describe a child's developmental levels, goals, support services to be put in place, the date and location services begin, and the name of the service coordinator for children birth to three. IFSPs are created when a child is enrolled in EI services, or shortly after, depending on a family's availability.

Although EI sites have shared eligibility data for referred children with EHDI for years now, we had some work to do to collect the initial IFSP dates. Julie reviewed EHDI's EI data for 2013 to identify children for whom we needed a first IFSP date. Then, she sent requests for the IFSP dates by secure e-mail to EHDI's EI contacts, listing the child's name, birth date, and ecWeb Child ID number.

Overall, the counties were wonderfully prompt and responsive, providing EHDI with many IFSP dates that we did not have before, allowing us to include this important data in our annual data report to the CDC, due in February. Thank you to all our EI partners for working with Julie on this year-end project!

Family Support Coordinator / Guide By Your Side Update:

Helen currently has six Parent Guides on the GBYS team, but is still looking for a Guide to serve families in Southern Oregon.

The Guides are in the midst of individual meetings with Helen to review their past year's activities and look ahead to this year's efforts. At this time, the Guides also evaluate Helen and the overall program (GBYS).

The GBYS team will be discussing goals for 2015 during the regular team conference call in February. Family events and educational workshops are being planned – stay tuned for more information.

In 2014, one Parent Guide has been dedicated to helping reduce loss to follow-up. Each week, the Guide receives a list of 20-40 families of infants who referred on newborn hearing screening but have not returned for diagnostic evaluation. EHDI has sent these families and their child's pediatrician letters encouraging them to follow up. Letters include information about the closest diagnostic facilities that can provide the needed type of testing. The Guide has provided an additional support and reminder to these families that it is critical that they pursue diagnostic evaluation for their children.

Helen is working to secure grant funding to send the GBYS team to the Hands & Voices Leadership Conference in September. It has been four years since the team last attended the national conference and this would be a terrific learning and professional development opportunity for the team!