

EHDI Staff and Advisory Committee: No changes to the EHDI team since our last report. There have, however, been a few recent changes to the Advisory Committee membership.

- Ginna Oliver retired from state service effective April 1st. A new representative to the Committee from the Department of Education has not been identified.
- Lyn Ayer regrettably stepped down from the Committee, but recruited the Director of the Teaching Research Institute at Western Oregon University, Ella Taylor, to join us.
- Patrick Graham, also from Western Oregon University, accepted the invitation to join the Committee.
- Diane Wiscarson regrettably withdrew from the committee.

Program funding details: We just received our latest Notice of Grant Award from the Health Resources and Services Administration (HRSA), for the period April 2015-March 2016. This NGA reconciles all HRSA funded states and territories to the same grant period.

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

EHDI Information Exchange for Hospital 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, an exchange with real data (!!) will be achieved - 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. EHDI and MCH Informatics staff presented a poster about this project at the 2015 National EHDI Meeting.

CDC Hearing Screening and Follow-Up Survey (HSFS):

Every year, EHDI programs voluntarily submit annual data to the CDC HSFS for analysis and publication. In February, Oregon submitted aggregated screening, diagnosis and intervention data for the 2013 birth cohort. These data are used for state-by-state comparisons of our progress in meeting the 1-3-6 goals. In preparation for data submission each February, the team tackles extensive data cleaning. Clean-up included a review of:

- 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, and detect any lingering LTD
- Early Intervention enrolled cases needing a first IFSP date
- Lists of 2013 LFU babies were sent to key audiologic providers to detect LTD (thank you!)

We are thrilled to announce that 71% of referred babies in the 2013 cohort received follow-up (LFU was 29%)! This is a significant improvement over 2012, when 52% of referred babies received follow-up (LFU was 48%).

Loss to Follow-Up:

HRSA-funded EHDI Programs are expected to achieve annual 5% improvements in our diagnostic follow-up rate. With recent analysis of final 2013 data, we achieved our three year HRSA target (5% annual improvement to reach 68% follow up by 2016) in ONE year.

Oregon EHDI's follow-up protocol includes:

Weekly:

- Letters to families of unscreened and referred infants directing them to screening and follow-up facilities
- 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 list to audiologists requesting status updates to records.
- Letters to families of HL babies not previously referred to EI by audiologist.
- Referrals of infants diagnosed with HL to EI at approximately 6 months 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 infants without documented follow-up at 6 months of age that includes a list of audiologists and survey to report hearing test results, scheduled appointments, barriers, or refusal to follow-up.

Periodic/On-going:

- Extensive custom follow-up activities for infants needing medical evaluation
- Public health nursing follow-up
- Extensive use of monitoring reports
- Technical assistance to partners
- Batched RFIs to known inconsistent reporters
- Offering QI strategies to audiologists

Trainings and Technical Assistance:

Guest Lecture at Pacific University: Shelby, Helen and Pam presented to Wendy Hank's second-year audiology students about the role of audiology in early intervention for young children and their families.

We have drafted a Public Health report on congenital hearing loss and the role of the physician in supporting EHDI 1-3-6 goals for electronic publication as a CD Summary. The intended audience for CD Summaries includes licensed health care providers; public health and health care agencies; media representatives; medical laboratories; hospitals; and other individuals and institutions with an interest in epidemiology and public health interests.

Birth Facility Performance Reports:

In March, we sent birth facility performance reports to all Oregon birth hospitals and screening birth centers. As in the past, performance reports provided summary statistics by quarter for ever screened, screened by one month, refer rate, timeliness of reporting, ever follow-up and follow-up by three months of age. Performance was compared to the state goal and the average of "like" facilities (whether mandated, voluntary, etc) for each indicator. Rankings were added to further illustrate the opportunity for improvement.

Audiology Updates:

We have been sending 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) help support audiologists in their reporting and data system navigation practices.

A draft Pediatric Audiology Best Practices protocol was distributed to all known pediatric audiologists. Comments were received and are being integrated. The final version of this document will be released soon.

Early Intervention Updates:

EHDl continues to partner with and provide technical assistance to those EI facilities who have agreed to receive automated EHDl referrals through the EHDl database.

Family Support Coordinator / Guide By Your Side (GBYS) Update:

Helen recently recruited and hired a new parent Guide for Southern Oregon. Brandie Henderson, mother to a little boy age 18 months who uses hearing aids, is a teacher in the area and has shown an incredible desire to ensure all Southern Oregon families are fully supported. Her training begins this month.

Helen is looking for another Guide for the Portland Metro area – please send any recommendations her way!

This year's annual Guide training is schedule for June 24-25th. Oregon Guides will be training with the Washington team again, and may be joined by the team from Nevada as well. Helen and the Washington Coordinator are developing the agenda, which will be informed by the annual reviews each team performs.

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 she feels strongly that it would be a terrific learning and professional development opportunity for them.