

EHDI team: No changes to team composition. Ben Spencer is working part time while in nursing school. Shelby Atwill began working as the school audiologist at Tucker Maxon in August. Heather is adding a new part time role as the MCH Child Care Consultant to her portfolio, due to a staff retirement and budget shortfall to hire a new public health nurse consultant.

Program funding details: EHDI is funded through grants from the CDC and HRSA, with limited in-kind evaluation and management staff time supported through the Title V MCH Block Grant. The CDC grant (\$163,500/year) is focused on the development, maintenance and enhancement of the EHDI information system and surveillance programs, with a keen focus on using evaluation for program improvement. The HRSA grant (\$250,000/year) is focused on reducing loss to follow-up at the 1-3-6 milestones through the use of quality improvement strategies.

As reported in July, as a result of the reduction in the HRSA budget, high state cost allocation, growing program expenses, and inability to rely on Title V for any spending overages, the EHDI program has a razor thin budget this fiscal year, with the possibility of a budget shortfall. We have taken a number of actions to remedy this potential budget crisis, including: requesting a small special administrative budget (\$16K) from HRSA to offset personnel, special project and cost allocation expenses; reducing the Guide By Your Side budget (reducing the annual training budget and outreach hours); reducing our travel budget for site visits; and migrating some of the Coordinator and Administrative Specialist salaries to other project budgets.

Meuy Swafford represented Oregon EHDI at the CDC Grantee Meeting in Atlanta last week. The meeting was specifically focused on data collection, reporting and use of data for quality improvement efforts. In addition to these topics, Meuy shared that there is interest both at the federal government and among our fellow states in looking at language, communication and education outcomes for infants who have been identified through the EHDI system. We will be initiating conversations to explore whether any Oregon EI/Regional Programs would be willing to partner with us in a small pilot project to examine available data and its meaningfulness in looking at our effectiveness as a system for developmental outcomes for our children who are deaf or hard of hearing.

All progress reports and any continuation application documents are available upon request.

EHDI Information System Updates: Meuy has made a number of updates in EHDI-IS, including:

- Receiving the first IFSP date from ecWeb (for use as the enrollment date)
- Updating screening and audiologist tables for automated referrals
- Adding fields for tracking LFU phone calls
- Creating reports for monitoring Guide activities and LFU phone calls
- Creating a new automated Request for Information fax template
- Updating the Nurse Referral process for automated trigger at the time of an EI Referral
- Redesigning the Guide By Your Side tab for easier data recording and analysis
- Added additional options to record provider response to our letters
- Addition of bloodspot provider data to EHDI-IS for use in follow-up

In order to support improved care coordination and communication for our families, we added a document uploading feature in our data system that allows audiologists to share useful information such as consents and more detailed evaluation findings with early intervention specialists. In the last year, twenty-two evaluations

were uploaded into our system for infants diagnosed with hearing loss. These documents were thus readily available for early intervention evaluation teams to use in the eligibility determination process. Though this feature is not used universally, the audiologists who are using it report finding it simple, fast, and reassuring in knowing that their evaluation reports are secure and received by the intended recipient. We hope to see more use of this feature in the future.

We have a number of reports available in the EHDI-IS for use in monitoring and quality assurance/improvement activities by both program staff and partners. For additional information or to suggest a QA report, contact Meuy at meuy.f.swafford@state.or.us.

SAVE THE DATE! We're hosting an EHDI-IS Refresher on Thursday, November 20th for our audiology partners to support complete and consistent data reporting. More information and a link to register is forthcoming.

EHDI Newsletter: Archived issues of the EHDI Newsletter are available on our website at <http://healthoregon.org/ehdi>, under the "EHDI Data, Reports and Newsletters" tab. Julie is considering a new approach to the newsletter – perhaps either in part or fully converting to an electronic format such as a newsfeed or blog. We welcome you to offer your input about that possible change, as well as any suggested ideas to make the newsletter useful for you! Please send your suggestions to: julie.a.hass@state.or.us.

Screening Updates: In addition to our biannual Hospital Performance Reports sent in July, we have also been sending regular Requests for Information (RFIs) to each Newborn Hearing Screening Coordinator. These reports offer a running list of infants who were missed, incomplete or who were reported to have referred on hearing screening. We ask that each coordinator review and confirm the reported results, and correct any inaccurate data in OVERS. These RFIs to coordinators have been very fruitful in drawing attention to reporting errors, inconsistencies, and opportunities to review hospital protocols.

Through these ongoing communications with our hospital partners, we have also learned of a number of changes in personnel for which we hadn't previously been notified.

We've added another midwifery facility to our group of midwife screening partners – Canyon Medical Center in Portland, Oregon. We now have hearing screening equipment placed with 7 midwifery practices (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 | Type of Loaner Equipment | Annual Birth Count (b), 2013 | Total # screens reported, 2013~ | Total # screens reported, Jan-present 2014~ |
|--|--------------------------|------------------------------|---------------------------------|---|
| Alma Midwifery (Portland) *screening since 1/2013 | OAE | 106 (b) | 126 (s) | 151 (s) |

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|--|-----|---------|--------|---------|
| Andaluz Waterbirth (Portland and Tualatin) * *screening since 8/2013 | OAE | 131 (b) | 30 (s) | 126 (s) |
| Bella Vie Gentle Birth (Salem) * screening since 12/2013 | OAE | 87 (b) | 8 (s) | 71 (s) |
| Canyon Medical Center (Portland) * screening since 9/2014 | OAE | 42 (b) | -- | -- |
| Growing Family Birth Center (Lebanon) * screening since 2011 | OAE | 13 (b) | 39 (s) | 40 (s) |
| PeaceHealth Nurse Midwifery (Eugene) * screening since 5/2014 | OAE | 137 (b) | -- | 28 (s) |
| Trillium Waterbirth/WiseWoman Care (Medford) * screening since 7/2014 | OAE | 70 (b) | -- | 13 (s) |

Loss to Follow-Up: As previously noted, we are striving to improve our follow-up rate by 5% each year. Our team just completed a series of intensive meetings to review our follow-up protocol and identify opportunities to change and improve the way we work to support infants in receiving services. Our follow-up protocol includes: requests for information to hospitals for final screening results, letters to families, letters to primary care providers, phone calls to families, fax back forms for providers, questionnaires for families, extensive custom follow-up activities for infants needing medical evaluation, public health nursing follow-up, extensive use of monitoring reports, technical assistance to partners, audits for audiologists, active case reports for audiologists, targeting of screening and diagnostic resources, and additional nuanced activities as warranted.

Public Health Nurse Updates: Julie and Heather worked with Caroline Neunzert, of the Oregon Center for Children and Youth with Special Health Needs (and this Advisory Committee), to create an EHDI case study for regional public health nurse trainings around the state. The case study is composed of a series of vignettes that illustrate the multiple steps, challenges, barriers, supports and sometimes serendipity needed for many of our infants who refer on newborn hearing screening to receive a diagnosis. Caroline used the case study with CaCoon nurses in 4 regional trainings, and we anticipate using it for the upcoming MCH nurse orientation next week as well.

We have been working with our state public health nurse colleagues to re-envision the process and protocols for public health nurse referrals for both our diagnosed and lost to follow-up infants. Finally, we are lucky to count Washington County Public Health and Lake County Public Health among our screening partners and Multnomah County Public Health a partner in more extensive loss to follow-up efforts.

Pediatricians and Other Medical Providers: We continue to send follow-up letters and requests for information to medical providers obtained through other public health program data systems. We recently began receiving provider names from the Oregon State Public Health Lab (OSPHL) for many of our infants needing follow-up. In general, we are finding these provider names more accurate than the provider names we've been receiving via the Immunization ALERT data system. As such, Meuy has programmed our system to use the bloodspot (OSPHL) provider as the default for our letter follow-up, with the Immunization provider as the second choice. We have also added additional data fields to collect the responses/information received in response to our provider letters. We hope to report at the next meeting on the effectiveness of our new source of providers, using our new data options. Options include: information already received, new provider info, not patient,

parents unresponsive, unable to contact, provider unconcerned, results reported or received, parent decline, referral made, appointment scheduled, no information received.

Audiology Updates: We continue to send audit lists to our audiology partners around the state. Currently, the following providers/facilities are participating: Legacy Audiology, Central Oregon ENT, Willamette ESD, PeaceHealth Hilyard, MidValley Hearing, Eugene Hearing and Speech, Providence Audiology, Oregon ENT in Medford and Audiology Associates in Grants Pass. OHSU has also agreed to do a very comprehensive data audit for us before we close our 2013 data. These audit lists include children who referred on newborn hearing screening but for whom we have no diagnostic evaluation results. We ask providers to review lists of children from their facility or region who meet these criteria and report results for any children they have seen but neglected to report previously.

We tested a new draft audiology Performance Report with Oregon ENT while at our site visit in July. It was favorably received, and we hope to improve and implement its use more broadly to help our audiology partners see their contribution to reducing loss to follow-up and to activate them to help us achieve our goal for 5% improvement each year!

This month, we began sending a new monthly data report 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. We are asking audiologists 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, will help 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) just generally stay on top of our workloads better.

Early Intervention Reporting: We ask our Early Intervention partners to report the outcomes of eligibility and evaluation determinations for all infants that we refer and any child who is considered for hearing impairment eligibility regardless of referral source. We report these aggregated data to the CDC during the annual CDC Data Survey. To simplify reporting, we ask that EI providers indicate EHDI as an ODE referral source and obtain and indicate consent to share data in the EI data system, ecWeb. These simple steps enable data sharing and reduce the burdensome process of reporting outcomes by phone or fax. Our efforts to build relationships with our EI partners and reiterate the importance of sharing referral outcomes are paying off. Prior to piloting our automated direct referral to early intervention, Oregon EHDI received eligibility and enrollment data for approximately 74% of our referrals for infants with hearing loss. As a result of our efforts to partner with local early intervention programs and the Oregon Department of Education, we now have access to eligibility and enrollment data for significantly more referrals (90%), with the majority of the data being received through data sharing (84%). We are still working to enroll the few remaining EI programs into this referral and data exchange process.

With the addition of Intermountain ESD, Southern Oregon ESD and Douglas County ESD, we now have 8 of the 9 Early Intervention Service areas participating in our automated referral process. This process allows audiologists to refer children diagnosed with hearing loss directly to the appropriate EI Program through EHDI

IS at the time of reporting. EHDI IS documents the referral details and an automated report monitors the receipt of the referral.

OTHER PROJECTS:

EHDI Information Exchange with Hospitals for Screening Data: Oregon EHDI recently learned that we have received short term funding to tackle Phase Two of the Clinical Document Architecture (CDA) pilot project in partnership with CDC and the Public Health Informatics Institute. We successfully completed our participation in the Phase 1 project 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 intent for Phase Two is to perform the exchange using real data from OHSU.