EHDI Advisory Committee Meeting Minutes

Healthy Places, Healthy People

Meeting Date:	October 20, 2016
Meeting Time:	9:00 am to noon
Meeting Location:	Providence Child Foundation Center
Meeting Purpose:	The purpose of this meeting is for planning coordination and collaboration.
Regular Attendees:	EHDI Advisory Committee and EHDI Staff
Attendees:	(Members) Eleni Boston, Stefanie Cozine, Heather Durham, Kelly Farrell-Oliverson, Ilia Fong, Pam Fortier, Melissa Gritz, Anne Heassler, Jeremy Hepp, Sharla Jones (by phone), Sheevaun Khaki, Ericka King, Cindy Kollofski, Chad Ludwig (by phone), Henry Milczuk, Angie Mulkey, Sara Ohgushi, Betty Shuler, Anne Smyth (OHA Staff) Claudia Bingham, Shelby Atwill, Heather Morrow-Almeida, Meuy Swafford, Vivian Siu, Stephanie Glickman (Guests) Claire Leake, Amy Kyler-Yano, Bryan Greenaway

Agenda Item, Objective and Background Information	Time
1) Networking	8:30-9:05
2) Welcome, Introductions, Review of Minutes – Eleni Boston	9:05-9:15
Discussion & action steps: Committee Chair Eleni Boston called the meeting to order. Reviewed agenda. Attendees introduced themselves. Brief overview of last quarter's meeting minutes. No changes needed	
3) Audiology Group Update – Heather Durham	9:15-9:45
Background: With our new term of membership, we're trying some new sub-committee/groups: audiology, health/medical, parents and community members, education. At each meeting, one or more of these groups will be asked to provide updates and lead a discussion about gaps/needs, opportunities, areas of focus, work that needs doing – how to strengthen the EHDI system from their respective vantage point in the EHDI neighborhood. Heather Durham is a pediatric audiologist at OHSU/Doernbecher Children's Hospital and discussed issues discussed at two meetings attended by several local audiologists. Topics included: 1. Discrepancies between ABR results. Each audiologist shared their steps to create consistency across the state. Clarifying steps for sedated ABR will also ease parental concerns. 2. Number of children with passing NBHS results who were later identified with hearing loss. Eight out of all children born in 2015 were identified. Common factors included ototoxicity, meningitis, or CMV.	

3. Suggestions for the webinar and who would like to participate. It should include an audiology piece, resources for providers, etc. 4. Children birthed by midwives: usually seen by midwife for six weeks followed by unknown status. Large population of our LFU children. Intend to identify these groups. 5. The process for getting reports into EHDI is convoluted. 6. Concerned about dispensing audiologists who will accept children patients outside of Portland. 7. Consistency in referral process. Intend to compile numbers and make recommendations for improvement. One issue is middle-ear fluid not clearing. 8. Standardizing the medical clearance form to make sure ICD10 codes are correct and diagnosis is approved by insurance seamlessly. Consider a billing guide for Oregon to make sure codes are in line with OHP coverage. EI should also have consistent ICD10 codes.	
4) Insurance Mandate – Eleni Boston and Heather Morrow-Almeida	9:45-10:10
Background: Follow-up from our April meeting when two parents of a late-identified child came to meet with the Advisory Committee to get your feedback on a few legislative concepts that emerged in prior key stakeholder interviews/meetings that they had conducted. **(See attached Draft Legislative Concepts)**. Based on feedback and feasibility, they are focusing on concepts 2,3,4,5 for this session. Funding doesn't require a bill. Loan forgiveness should be straightforward. Regan unable to be at the meeting today, but requested that the committee: A) Offer recommendations to update the current Oregon insurance mandate for devices, minimum coverage amount, services to add, etc. B) Volunteer to provide subject expertise as they develop the bill and work it through session **(See attached insurance spreadsheet)** Questions: what should be added or changed to this law to strengthen it for families and to ensure children can optimize their potential language and communication? Discussion: • More coverage for hearing aids (reach out to California to see how they are accomplishing this) • Clarification of "devices" • ASHA benefit plan has some out-of-date areas, like cost numbers: private insurance should match ASHA • Hearing aid replacement frequency should be consistent • Clarification regarding hearing assisted technology	

• Replacement for ear molds should include once per year after 7 years of age • Coverage for cochlear implants seems low • Explicit coverages regarding FM and hearing assisted technologies • Language should be consistent with definitions • BAHAs and soft bands for children of all ages (not just under 5) • Include language regarding appropriate amplification • Coverage for hearing aids too minimal • Coverage for processors too minimal • Due diligence on the insurance to inform parents of their coverages and ensure claims processed correctly • Include measures to help families obtain coverage more easily • Liaison to help families • Bill should be broad, and when it is passed it gets referred to administrative rules where law becomes more focused and specific • Provider shortage • Education for both parents and providers regarding insurance coverage • Inclusivity in the bill may narrow coverages	
5) EHDI Data Update – Vivian Siu	10:10-10:25
(See Vivian's Powerpoint slides) This data is current as of October 2016. Only two non-mandated hospitals are non-screening facilities and this is where babies are consistently not getting screened. Discussion: • Number of children born at birth center or homebirth = 1200-1600 babies • We should examine why EI enrollment varies: parent refusal, LFU, ineligible, etc. • Some infants born in another state are related to Oregon and can be difficult to follow up	
Break, Stretch and Networking	10:25-10:40
6) Update from Regional D/HH Coordinators with discussion – Eleni Boston	10:40-11:15
Changing Landscape in Education Programs for Children with Hearing Loss: Oregon Regional Programs Oregon School for the Deaf **(See handout)** Key points of presentation: • Magnificent funding for equipment • Soundfield system in schools • Unilateral hearing loss could be the results of kids getting screened early (before, unilateral loss was not identified until school age): there are a lot more options for kids with unilateral loss • 504 plans (provides some accommodations without individual education plan	

- Two years ago, the School for the Deaf had a group of high school students who graduated: first group of kids identified at one year of age (three in honors classes, one senior class president, some earned scholarships, etc.)
- Factors which increase late identification: not strong in English or Spanish (of kids where ESL), students taking other languages in school, etc.
- Challenges they face include: different educational strategies being employed (ie. not providing resources to students in mainstream with hearing loss, not using SL interpreter until 3rd grade because they think the child needs direct services, etc.)
- Need to address validity of statistics: are we catching hearing loss earlier so it seems more prevalent?
- Need to address how we are working with bilingual children
- Need more statistics help from EHDI
- Rely on GBYS for families who do not want to talk to ORP OSD

Discussion:

- Teacher education? Depends on school district and their philosophy. Salem has huge push for total inclusion.
- If a child is in a mainstream environment, they are getting IEP or 504. This person can educate the teacher. An SLP or school counselor is another option. In Salem, the SLP is writing the IEP and they take on the coordinator role and are the fall back person for the counselor. However, counselors are there 100% of the time, SLPs are not.
- Concerns about early childhood participation and children in childcare/preschools. Current work to mitigate this:
    - Teachers of the deaf are going out to preschools, daycares, and Headstart (Headstart is a very noisy environment)
    - Auditory verbal and ASL only preschool
    - Toddler group and home visits for infancy (dependent on the EI program in their area – would like more in-service and training to EI agencies)
- Need: a list of services offered by regional programs

Eleni commented that regional management team will take recommendations, make recommendations, and take forth to SACSE and SICC (sp?). Focus groups at Tucker, Columbia, Willamette, and NW Regional. 15 families were interviewed with discussion. Not willing to share anything specific until data analyzed. Will report final on December 31, 2016 to include demographics. New year: focus townhall meetings (???).

Update from GBYS: Transition in Portland area: Monica is moving on. Position opening in Portland area. Continue to recruit guides in Salem. Always need parents with bilingual capacity. Parent guide with ASL experience (from the beginning of their child's experience). Parents with more diverse diagnoses and

treatments. Next meeting GBYS may have more exciting information for national activities. They may be a pilot group for (Heather, did you catch this part?).	
7) EHDI Program Update – Heather Morrow-Almeida	11:15-11:35
(See Presentation slides) Grant gives us specific requirements. Families and stakeholders to tell us where the gaps are and where we need to go. Includes many ambitious goals. Discussion: • Concerns about funding • Concerns about how to achieve high rates of diagnosis by 3 months • Concerns about how other states report data • Concerns about three months to EI referral (realistic?) • Concerns about less proactive families and meeting these goals • Need county/regional level input and map to find gaps and make recommendations	
8) Status and Updates: ongoing efforts – Heather Morrow-Almeida and Eleni Boston	11:35-12:10
Topics to address in our learning communities: • OAA conference changes • Webinar opportunities as a starting point • Headstart hearing screenings: how they are recorded and communicated • LFU factors • Diversity and cultural awareness • Access to materials and resources on how to support a child with hearing loss (since it is uncommon) • List of red flags for what could be hearing loss and who to refer to • Share resources online • Share experiences of in-classroom (what it really looks like when a child has hearing loss) • EHDI to put together a presentation to EI ECSC contractors • Training on how to use EHDI system • Identify gap topic • Primary care doctors: when should they be suspicious of hearing loss • Training to providers to be advocates at diagnosis (sometimes no advocacy until they enroll in a school, should start with PCP) • Connecting education and medical component: integrate early educators and medical groups • Parent and or deaf member at the clinic of diagnosis (to help encourage family to show up to future screenings and diagnosis – parent perspective is more helpful and unique than a medical professional)	

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9) Other Business, Next Meeting Detail, Close of Meeting – Eleni Boston	12:10-12:15
Need a volunteer from medical or family group to present strengths and opportunities at next meeting.	
Items for future meetings:	
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