EHDI Advisory Committee Meeting Minutes

Healthy Places, Healthy People

Meeting Date:	August 18, 2016
Meeting Time:	9:00 am to noon
Meeting Location:	Columbia Regional Program
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, Heather Durham, Kelly Farrell-Oliverson, Ilia Fong, Patrick Graham, Melissa Gritz, Anne Heassler, Nikki Hinsley, Sharla Jones (by phone), Cindy Kollofski, Denise Kossover-Wechter, Henry Milczuk, Angie Mulkey, Sara Ohgushi, Betty Shuler, Anne Smyth (OHA Staff) Claudia Bingham, Shelby Atwill, Heather Morrow-Almeida, Meuy Swafford, Vivian Siu, Stefanie Krupp (Guests) Kristy Karsten (Columbia Regional Program), Lisa McConachie (Columbia Regional Program), Linda Brown (ODE), Cory Scott (OHSU extern), Denise Thew Hackett (WOU), Claire Leake

Agenda Item, Objective and Background Information	Time
1) Networking, New Member Welcome	8:30-9:00
2) Welcome, Introductions, Review of Minutes – Eleni Boston	9:00-9:15
Discussion & action steps: Committee Chair Eleni Boston called the meeting to order. Reviewed agenda. Attendees introduced themselves. Brief overview of the role of the EHDI Advisory Committee: to advise the EHDI program, contribute to the legislative report, work to improve the EHDI system. In addition, to use individual role and sphere of influence to meet EHDI goals. Orientation to Oregon EHDI power point slides are attached.	
3) Early Intervention Eligibility Criteria Discussion – Linda Brown	9:30-10:15
Linda Brown, a Regional/Educational Specialist with the Oregon Department of Education attended to update the committee on next steps to advance the committee's recommendation to expand the eligibility criteria for infants and children with hearing loss. Background and context: EHDI Advisory Group is requesting that OAR 581-015-2150 be revised. The purpose of this revision is to 1) expand the eligibility criteria which would allow infants identified with a minimal hearing loss to be eligible to receive services to prevent language and communication delays, and 2) streamline the process to prevent and reduce delays in the process of eligibility determination by allowing the audiologist, who is the medical specialist who identifies the hearing loss, to complete the medical or health assessment statement necessary for evaluation.	

The Joint Committee on Infant Hearing, which is a multi-disciplinary body of experts including the American Academy of Pediatrics, the American Speech Language Hearing Association, the American Academy of Otolaryngology and Head and Neck Surgery, the American Academy of Audiology, the Council on Education of the Deaf and the Directors of Speech and Hearing Programs in State Health and Welfare Agencies, declared in their 2007 Position Statement that "all families of infants with any degree of bilateral or unilateral permanent hearing loss should be considered eligible for early intervention services". Also from the JCIH Position Statement: "Before newborn hearing screening was instituted universally, children with severe-to-profound hearing loss, on average, completed the 12th grade with a 3rd- to 4th-grade reading level and language levels of a 9- to 10-year-old hearing child.[81] In contrast, infants and children with mild-to-profound hearing loss who are identified in the first 6 months of life and provided with immediate and appropriate intervention have significantly better outcomes than later-identified infants and children in vocabulary development,[82,83] receptive and expressive language,[12,84] syntax,[85] speech production,[13,86–88] and social-emotional development.[89] Children enrolled in early intervention within the first year of life have also been shown to have language development within the normal range of development at 5 years of age."[31,90] An early investment in these infants and their families is a win-win for the child and for the system. There are other states which have more inclusive eligibility criteria. Oregon has considering making similar revisions in the past. Revisions will mean that infants diagnosed with minimal hearing losses, which can still be impactful to the child's ability to hear soft sounds, to hear clearly in settings with poor acoustics (like a classroom), will be able to access the family coaching, training and supports early in the child's life, likely preventing delays in language and communication development, as well as assessment and monitoring to assure that the child is developing on track. It may also mean that these children have access to audiology services for hearing aids, which can be difficult for families in many parts of the state. Committee members provided their input to inform and lend support to the decision to make Oregon's hearing impairment eligibility criteria more inclusive: • Evidence to inform revisions • Current criteria is impeding meeting national goals • Consider all factors like secondary or primary disabilities in addition to hearing loss • Children not being identified until kindergarten are already entering school with a deficit	

- Unilateral hearing loss is still hearing loss - makes it difficult to locate where sound is coming from, joining group conversations in school, affects social and emotional development
- Speech and hearing takes two ears based on the design of the brain. Deficit in one ear makes the brain work that much harder in addition to the other learning and development going on early in life.
- Public Health perspective is prevention - prevent delays, more efficient to serve families early
- Only a few db loss creates risk for learning delays and progressive loss
- Mild hearing loss - parents think their child is fine, then move forward as if the child has no special needs, but miss the subtleties of communication. Parents don't enforce children wearing hearing aids because they don't see a significant difference. Otherwise if parents are concerned, providers say "don't worry". They see something is not right, but don't have support. So much lack of understanding in early intervention. They don't know what they are missing.
- Identification early of unilateral and mild hearing loss for Head Start population but no intervention until they need speech and language but they don't get hearing support. Head Start is a noisy place for kids which can create added difficulties for children.
- Children do not know how to self-advocate. Children don't want to be different so they will often not speak up.
- Can potentially save the ODE money by getting these kids identified earlier with the support they need

Committee members raised concerns about criteria only changing for EI (birth to three). Need to minimize the differences - maintain consistency for families, at the very least birth to 5 years

Next steps for process:
Supporting information and proposed changes will be shared with regional management team, ODE, State Advisory Council (in January), State Coordination Council (in January), to Directors before going to the Board.

Legislators will ask for studies showing how changing the criteria may decrease cost for education services later on, despite an initial increased cost for EI. Need to ask the question how much this might affect costs to State.

Rough estimate about 100-200 students that would be considered not eligible now that need services.

Medical statement signature - signed by MD now, can it be a PA, NP, Audiologist? ODE is open to being more inclusive of other health care providers

Action step:
Present a formal proposal to ODE to change not only Part C (EI) but also Part B so it

moves forward with changes together through the rest of the approval process.	
4) Break, Stretch, and Networking	10:15-10:30
5) EHDI Data Update – EHDI Team	10:30-11:00
Discussion & action steps: Vivian Siu (OHA research analyst) gave the quarterly update, attached.	
6) OAD Update, Community Assessment – Denise Thew Hackett	11:30-11:45
Discussion: Denise Thew Hackett, an Asst Prof at WOU, attended the meeting to update the committee on the Community Needs Assessment, a project to collect information on how well Oregon is meeting the needs of the Deaf, hard of hearing and hearing loss communities. The project originated with Senate Bill 449 from the 2015 legislative session, which was focused on the creation of a Commission for the Deaf and Hard of Hearing. Oregon is one of only 13 states lacking this agency. The bill resulted in funding to collect more information to determine the need for these communities. The research team collected data using a survey, focus groups and key informant interviews. The survey was offered in English, Spanish and ASL. Able to complete on mobile devices. Specific areas of focus are: abuse, alcohol & drug treatment services, education, employment, health and mental health services, housing, government services, and transportation. The researchers are to present the findings to the legislature during the 2017 session. To date, there have been 700 survey responses, but Denise is hoping for about 1000 more for statistical purposes (ideally 2000 total). About 30% didn't answer all questions so may not be useable. Errors with survey completion may also reduce countable number of surveys. Survey went out via listservs, Facebook and social media. May be missing populations not connected to routes used. Denise is looking for support to connect with DHH communities across the State. The survey is primarily written for and directed to adults but children can take it with adult help. Parents can take the survey for their deaf children. Committee members expressed concern that the survey questions do not seem very relevant or applicable to young children, and that parents of children with hearing loss are struggling to participate. There are concerns that the these members of our communities will not be adequately represented in the findings and report to the legislature.	

Committee members suggested holding focus groups to gather additional data specific to parents of children who are DHH. Action Steps: Email Denise Thew Hackett with any questions. Call to committee and guests to send along link to reach more of the DHH community within Oregon.	
7) Audiology Report Out – Heather Durham and audiologist members	11:00-11:30
Discussion: Background: Audiologist perspective - have been focused on screening and diagnosis but improvements can and are being made. Audiologists get data that can be used to be more inclusive and support improvements to the process for all stakeholders including medical professionals and families. Columbia Regional Program just hired a new audiologist (Kate Chamlou), so now have 4 audiologists this academic year but will have one leave next year and will be down to 3 again, which is an adequate number. They received increased funding for BAHAs, provides amplification for conductive or unilateral hearing loss. Vibrate sound through the skull rather than through ear; able to get more FMs (assistive devices for speaker or personal device to amplify teacher in classroom). Providence is trying to develop a cochlear implant team including an Oregon ENT cochlear audiologist. Committee recommended adding parent and DHH person with CI to team. Legacy is creating a hearing aid program; added another audiologist (Greta), OHP provider except for FamilyCare, not taking LifeWise anymore. Tucker Maxon is rebuilding the clinical program and can take private health ins including Kaiser and OHP. OHSU (CDRC) is forming a team in their hearing loss clinic, including an audiologist, speech pathologist, otolaryngologist, developmental pediatrician (and geneticist?); clinic runs twice a month for a half day but looking to expand to two full days. Identified that some healthcare providers such as pediatricians or family practice providers are not making the appropriate referrals or supporting follow-up for screening or diagnostic audiology. Perspective from ND midwife: find ways to educate providers about resources, provide screening options at alternative locations or at midwives clinics/birthing centers. Action Steps:	

Looking to improve follow-up. For example, child found to have fluid and can't be seen for follow-up in two weeks, maybe consistently recommend 4 weeks if more likely to be able to complete visit/Dx. Explore ways to use advisory committee and EHDI team to reach more health care providers regarding HL and best practices for referrals.	
8) EHDI Goals and Assessments – EHDI Team	9:15-9:30
Discussion & action steps: Heather discussed the requirements for the new HRSA funding opportunity (2/3 of EHDI funding). Provided assessment tool developed by EHDI programs in other states, based on the 2013 JCIH update, to use in developing the EHDI work plan for grants and focus of committee efforts. Action Steps: Assessments to be completed and returned to Heather within 2 weeks. Heather will email the assessment as well, and will update the group at the next Advisory Committee meeting in October.	
9) Other Business, Next Meeting Detail, Close of Meeting – Eleni Boston	11:45-12:00
Next meeting date and topic: October 20, 2016 – Providence East, Child Development Center, 833 NE 47th Ave, Portland	
Items for future meetings:	
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