

Early Hearing Detection and Intervention (EHDI) Advisory Committee Agenda

Thursday, October 19, 2023

10-3 p.m.

Location: Heartland AEA, Johnston Office, 6500 Corporate Drive, Johnston (Johnston REC - Conference Room 141)

Welcome & Introductions

- Committee member check-in
 - Welcome Megan Palmer, Au.D,CCC-A, Mercy Ear, Nose and Throat in Cedar Rapids, IA
 - Welcome Hailey Boudreau – HHS Screening and Management Section Supervisor, Bureau of Chronic, Congenital and Inherited Conditions
 - Welcome Chantell Broome in non-voting capacity, awaiting formal administrative approval as a parent advocate (taking the place of Alison Kupka)
 - Welcome Susan MacDonald – current Iowa Association for the Deaf president as a Deaf Advocate (taking the place of Barb Carlin), awaiting formal administrative approval
 - Barb Pline from Keystone AEA is here in place of Annette Hyde Representing AEA Special Education
 - Additional Advisory Members in Attendance:
 - Lisa Anderson, Iowa Ear Center (SLP)
 - Susan Brennan, Director - Iowa Deafblind Project
 - Teresa Hobbs, Northwest AEA (Early ACCESS)
 - Tonya Krueger, Child Health Specialty Clinics
 - Tina Caloud, Iowa School for the Deaf
 - Elizabeth Woods, Heartland AEA (TDHH)
 - Stephanie Childers, Mississippi Bend AEA (Educational AUD)
 - Rita Fredericks, EHDI Staff (Follow-up Coordinator)
 - Heather Dirks, EHDI Staff (Family Support Coordinator)
 - Linda True, EHDI Staff (Follow-up Coordinator/AUD Support)

Announcements (Linda)

- Advisory Personnel Updates
 - Dx Audiology Provider in Medical/Clinical Setting (approved) – Megan Palmer
 - Deaf Advocate (In Process) – Susan MacDonald (IAD President)
 - Parent Advocate (In Process) – Chantelle Broome
 - AAP Chapter Champion (In Process) – currently recruiting
 - Family Practice/PCP – currently recruiting. Requested advisory member input on possible candidates
 - ISD Updates (per Tina Caloud)
 - ISD is growing – more students are growing and are serving both Iowa, Nebraska and South Dakota
 - ISD is growing in their outreach program in teaching ASL with activities
 - [ISD Website link](#) has an ASL link for accessibility

- ISD Pumpkin Patch in LaMars at Harvest Hollow and Dittmers in Council Bluffs (200 last year) tonight. Expecting 350 to attend between both locations
- [November 4th – Exploring ASL](#)
 - Free to Attend
 - Presenters and Performers
- November 12th in Ankeny – THRIVE Together
 - Meal served from 4:00-6:00
- Annual CDC Report Update
 - Evaluation report, performance report and preparing or large individualized data file due in November. Also will be submitting the annual aggregate survey in December (HSFS – Hearing Screening and Follow-up – survey for CDC). Jini Cox and Tammy O’Hollearn completed the data match and our new epidemiologist (Toby Yak) will be responsible for the coding for the individualized data file.
 - The EHDI program has had three epidemiologists within the past 18 months. The new EHDI epidemiologist is still learning our program.
- HRSA Grant Update
 - Provision for Language Acquisition Outcomes – addition to former goals for 1-3-6 and Family Support (added in last grant cycle). This will mean a continuation of the partnership with EA to also look at progress for children in the area of communication, which is looked at in the Early Childhood Outcomes (ECO):
 - 1 of the 3 areas that are measured -
 - Positive Social-Emotional Skills
 - Acquisition and Use of Knowledge and Skills ****
 - Use of Appropriate Behaviors to Meet Needs
 - For Acquisition and Knowledge of Skills – how do we look at Communication skill development (Teresa Hobbs to help with this) – and how might our partnering with EA help us to look at these outcomes (we don’t want to recreate the wheel or duplicate something that is already being measured by the entity impacting that most.
 - “Language Acquisition Outcomes” was not defined by the current grant and to what that means specifically not what variables are being measured, but HRSA guidance said that would be defined by each state and how to show progress in this area would be defined by each state.
 - Teresa Hobbs was asked to explain the process of data collection in the IFSP process:
 - Teams start collecting data at initial IFSP and continue until exited at age 3. Example: if a child came in at 5 months old their annual review would be 12 months later, so the team could have 3 meetings, three data collection points
 - EHDI staff may be able to partner to see this type of data to monitor language development and progress in communication skills over time
 - Question from Tina Caloud: How is this data shared with the public or will it be?
 - Response from Linda True: No names/identifying information will be attached to data. EHDI will be looking at overall progress and outcomes. EHDI staff will need more guidance as to how we could share that data. Additionally, EHDI is unsure of what the data is going to be used for, as

there has not been guidance regarding the utility of data from the national level.

- Question from Tina Caloud - with data sharing agreement, we are not collecting data ourselves, partnering with EI already collecting data which can be shared with LEAD-K progress moving forward.
 - Response from Linda True: EHDI has a data sharing agreement with Early ACCESS. Unsure of how language acquisition data will be combined with LEAD-K progress. That might be answered with committee member Tori Carsrud moving forward.
 - Provision for sustainable hearing screening services up to age 3 (including all children, not just those with risks) – we will be gathering data to see how we can develop partnerships for monitoring this and what that means statewide within the first year, and implementation will follow over the rest of the grant cycle.
- Question: Are there pockets of children that we are missing in the state?
 - Answer from Linda True: We have and will continue to gather data on that. Data has been shared previously regarding areas of the state and populations of Iowans that may be more prone to Lost-to-FollowUp.
- Committee Member Announcements (All)
 - Tonya Krueger - Iowa Family Leadership Training Institute for 2024 is taking applications.
 - Applications are due January 12, 2024.
 - Training is open to parents with children ages 3-19
 - Training will be held in the Cedar Falls/Waterloo area
 - Tonya Krueger will send flyers via email for EHDI to send out.
 - Lisa Anderson – Iowa Ear Center is doing a trunk or treat and wanting to do a Christmas event or Valentines event\
 - Send to Heather and she will share with families
 - Dylan Hauer from [Telecommunications ACCESS Iowa](#) will be attending
 - Susan Brennan – California doing a recording for families regarding USHERs – doing LSM (Latin Sign Language)
 - Susan Brennan – Update on Deafblind Project Grantee Award
 - Legislators provided additional funding
 - \$107,000 per year to run the grant
 - Currently, there are 110 people on our list age 0-21
 - Interveners – OSEP wants this to be addressed. Provides access and information to students, one-on-one, helps with environmental information and communication (not a para, not an interpreter) We are assuming some of the additional funds awarded will be used for specific intervener work
 - Any movement in getting interveners recognized in Iowa? Very fluid right now, not enough parent voices to articulate that this is a need
 - Unseen Documentary – Deafblind Project is having a virtual viewing party tonight in support of National Family Association for Deafblind
 - Change in staffing at Iowa Deafblind Project - Sara Harms is the new project coordinator as Katy Ring has moved to a new position with ISBVI

- 2023 AAP Statement – Hearing Assessment in Infants, Children and Adolescents: Recommendations Beyond Neonatal Screening.
 - Multiple organizations had concerns that the previous 2009 statement included language that was ableist and biased:
 - There has been an improvement in language used in the current 2023 statement to be considerate of provider bias – such as “loss,” “failed,” and “impairment” that was seen in the AAP 2009 statement. This language has been removed to reflect that children with hearing differences are “equal, healthy and whole.”
 - EHDI appreciates the wording in the new statement, but has decided to wait to link it on our website until all stakeholder concerns have been addressed. We are aware of the controversy. EHDI continues to follow the JCIH best practice guidelines which are endorsed by the AAP and has a more stringent, evidence based guideline for audiologic monitoring of children with risk factors. Iowa EHDI is waiting for agreement of stakeholders before we add this to our list of resources.
 - Concern: not mentioning audiologists as primary providers for a child’s hearing healthcare journey, other than hearing screening
 - Concern regarding statements surrounding language deprivation that have caused pushback from the American Cochlear Implant Alliance, some researchers from the OCHL study, as well as educational audiologists.
 - EHDI agrees with the new statement in that we don’t wish to wait on technology choices before promoting language acquisition options.
 - Evidence on learning signed language does not inhibit spoken and listening language.
 - At this time we are going to remain with the JCIH statement

EHDI Family Support Updates(Heather)

- EHDI Family Support offers support for families with a child with HD from birth to age 3.
- Book Club for Tots/New to the Journey Groups – monthly
 - Book club meetings held via zoom
 - First 10 families get a book
 - have 4-5 families each month
 - many requests and interest in programming from families, other states and other stakeholders
 - received a Prairie Meadows Community Betterment grant to support this program
 - book club is not recorded so that this is a safe space
 - ISD has recorded many of the videos, so we can send the family a link to the recorded book
 - National EHDI Presentation – Book Club Program
 - Abstract for National NCDB for National EHDI Conference
 - Parents enjoy meeting member of the Deaf Community
 - Next Book Club is Saturday this month
 - Survey Results
 - parents enjoy meeting members of the Deaf community
 - it can be difficult keeping toddlers engaged with zoom
 - parents enjoy learning new signs to use as a family

- parents appreciate not reading the book word for word but learning signs and strategies to communicate about the story
- New to the Journey Groups - quarterly
 - Continue to obtain parent feedback on what they are interested in learning about
 - September meeting on zoom: IEP toolkit, which was recorded for future use
 - January meeting will continue to do a deep dive into IFSP/IEP and parent rights (January 20, 2023 from 9:00am-10:30am)
 - Offers a different topic for families
 - Resources for families on a different topic
 - Previous have been a siblings panel
 - Question from Teresa Hobbs – how can they find the New to the Journey
 - Response from Heather Dirks: registration links for upcoming New-to-the-Journey meetings/events will be on the Calendar of Events for Families
- Family Outreach/Family and Deaf Partner Matches
 - Parent Partners
 - Partner Recruitment and Training
 - 30 families matched with parent partners since onset
 - 4 currently partnering
 - 15 partners currently trained
 - small stipend offered for parent partners
 - looking for parent partners that have a child with unilateral hearing loss or mild hearing differences
 - Surveys to Parent Partners have been sent to partners and families. No families responded, but there were some parent partners that responded
 - Feedback that there was good connections, but would like more time to work with families
 - Not enough time and money to support more time
 - Budget limitations to EHDI program
 - Enjoy working with families
 - Would like a more streamlined process for stipend
 - Created a google form to streamline
 - Concerns that partners were more geared toward mothers and would like more training for father
- DHH Partners
 - 19 Families have been paired since onset
 - 3 currently working together
 - 9 partners trained
 - Survey to Deaf Partners indicate these responses:
 - 50/50 on right amount of time – families and partners are both requesting more time
 - Appreciated ASL interpreters for the meetings
 - Meeting well organized and professional, interpreters were helpful and tips were appreciated
 - Request more meetings and time

- Families easy to work with
- Additional funding requested
 - Survey indicates these responses from Parents:
 - DHH partners helpful
 - Need more contact time
 - enjoyed hearing perspectives from DHH adult
 - Liked learning more signs, and mindful of signing when at meetings
 - Surveys continue to be collected to for continual improvement of process
- Family Support Community Events Updates Since April Meeting
 - Trying to do more events – trying to work with other agencies to be more inclusive for families
 - 19 families attended pumpkin patch
 - May Day – 9 families
 - Back-to-School – New to Journey
 - Pumpkin Patch – last and this year
 - Survey for 2023 pumpkin patch
 - Liked that TDHHs were involved in Central Iowa Locations
 - Site was expensive
 - Families enjoyed
 - Teresa Hobbs: Question about data for other languages
 - we have 3 children in the past year
 - use language line if needed or interpreter
 - Distribution Lists
 - monthly newsletter
 - share events throughout the state
 - 115 families enrolled and a handful of TDHH throughout the state
 - Please share so that we can share family events on that list
 - Family Needs Survey (Spring 2023)
 - Requests
 - Safety
 - IEPS/IFPS
 - Technology
 - Supports
 - Sharing of resources
 - Community Events
 - Meeting other families
 - why not attending
 - Age of child
 - scheduling conflicts
 - availability
 - Reminder that we are recruiting for parent partners who have children with unilateral hearing differences and New-to-the-Journey topics.

Learning Opportunities – Brainstorming Session (Linda)

- Question to Advisory: What are some things you would like PCP providers to know:
 - Need for CMV discussion, support for families and OBs should be having the discussion as well as, it is not happening in the manner it should
 - Parents/Providers aren't aware of the 21-day testing
 - Megan Palmer – getting a lot of parents in who have no idea if their child has had CMV testing
 - Medical provider training to reframe how they are informing parents their child has hearing differences – bias in language used (i.e., failing,” oh so sorry...” assumption of parent feelings on dx, etc
 - Tina Caloud willing to participate in training
 - Linda True shared that there will be an upcoming training with Cassie Garner of Boystown that will address some of this issue
- How to engage each entity, broaden outreach
 - End of Webinar Survey/Certificate of Attendance Update
- Current Topics for upcoming year
 - OTC Hearing aids and Impact on EHDI population, October 26, 2023(noon)
 - Iowa has passed legislation that allows OTC hearing aids to be sold. For most of our population this will not be an option. Education need for parents so that they know options for hearing aid needs and concern that parents may consider fitting children with OTC aids out of necessity
 - ABR dx tips, trick December 6, 2023 (noon)
 - Caitlin Sapp will present on this topic
 - Would like the discussion following ABR and diagnosis to be discussed
 - To be scheduled Spring 2023:
 - Update on Iowa's 1-3-6 progress
 - Looking at Iowa's progress and comparison to national numbers
 - COVID challenges and Iowa's ability to bounce back
 - Survey results from parent and provider surveys (EHDI Epi)
 - Looking at how parents and providers responded to consider barriers and strategies to overcome barriers
 - Comparing/contrasting responses from parent and provider lenses to allow more empathy among stakeholders
 - Training on how to access individual data for a facility (hospital/audiologists)
 - Best Practices in referrals for Early Intervention/Early ACCESS
 - Cassie Garner (to be scheduled in Winter/Spring 2024)
 - Appreciating that AEAs have videos, but they may be limited to the region they are in, and requesting more broad overview of Early Intervention strategies and discussion with parents
 - EHDI staff have found providers are having a hard time with the conversation. Concern is that providers are deciding that family is “not ready” for the Early Access conversation.
 - How to navigate if parents aren't ready, options for timing of this conversation

- o How to keep the discussion and appointments of amplifications options and conversations about Early ACCESS referral as different, so that parents do not think these two things are linked (i.e., can only receive EA if they come for a hearing aid evaluation or if they consider HAs).
- o Families Support
 - CMV education for parents
- o Provider Learning
 - CMV
 - Reframing the conversation around hearing differences
 - Keeping bias out of conversations
 - Tina Caloud and Susan MacDonald commented that they would be willing to be a part of this conversation

Update on EHDI Website Changes (Rita)

- Upcoming changes to website content will involve past requirements due to legacy IDPH requirements, (i.e. not having the same links on multiple pages and links resources page that is not an additional page on our website)
- Graphic and layout changes
- Not as many links on multiple pages
- Maybe more of a links resources page instead of links on multiple pages
- Protecting resources from outside journals (i.e. journal articles may not be directly linked)
- Trying to make changes to original source links
- Do people use certain things on the website that you would like as a hotlink?
 - o Hearing Aid Funding
- Susan asked about the 508 compliance needed – ours is for the HRSA grant, but the department is also pushing that (for accessibility for people who are blind and visually impaired)
- Hailey Boudreau added that there will be changes as the overall website, and that our current website is in the process of transition to allow easier access. One thing that has been discussed is an offshoot website for providers or families to refer to for specific resources that may not “live” on the main website, but will be accessible from the HHS site.
- Hailey Boudreau notes that there will be changes to the overall HHS website designed to allow easier access to the information for all website “visitors.”
- Please give feedback to us about places you use, please forward to Rita and Tammy
 - o Teresa Hobbs noted that she likes our website and it is easy to navigate

Update on EA/LTF/Provider Surveys (Linda)

- 15 parents sent gift cards for their participation in completing the surveys. Not all parents requested gift cards.
- Surveys sent incorporated ideas/insight submitted from Advisory member feedback
- First Round sent in July 2023, second round sent in August 2023 for all parent surveys.
- Parent surveys sent via text
- Provider Surveys were sent one time via email
- Will be analyzed following submission of the large data file and then will share results with EA during our monthly 1/2 hr referral and enrollment data meeting to brainstorm next steps (planning mtg, etc). Results will then be presented to advisory and providers by EHDI director and/or EHDI epidemiologist.

Update on Communication Milestones (Linda/Tori)

- Linda True thanked Advisory for all their work put in to gather sources and give input.
 - After gathering data and consulting with Tori Carsrud at the DE, it was decided that there are a wealth of communication resources available from the input provided by members (ex. Indiana's ASL milestones, Susan Brennan's contribution of how milestones may not have a timetable for children with deaf blindness).
 - The current spoken language milestones will be replaced by a communication milestones page that will allow people to check on milestone guidance that meets the communication needs of their child and the modality of communication (which might be a formal language such as English or ASL, or a communication mode like an object schedule or a tactile signing system) to meet their families communication needs.
 - Communication Milestones page will be updated to include resources for parents where they can link to these information about communication options, as well as resources to agencies that will provide support in developing communication for the individual child as well as within the family structure.
 - The intention is NOT to reinvent the wheel, but allow parents to find what they need for building a communication system of their choice within their family and find support to build that language system, and support language acquisition by their child with hearing differences.

Audiology Quarterly Reports? (Linda/Heather)

- Currently we have quarterly reports for hospitals and facilities providing the birth screening for newborn hearing screening. This helps BSP to know how they are doing with the meeting hearing screening by one month of age. Current question is looking at ways to show that EHDI is looking at performance of offices, facilities and providers doing outpatient and diagnostic testing to ensure that they are meeting the goal of diagnostic provision by 3 months of age.
 - Outside Working Group Commitments?
 - Question for Tammy – are there other states doing this?
 - What variables would be important for providers?
 - Would this help providers with QI?
 - How much time between the birth hospital and them contacting me for an appointment?
 - What are the parents told when they did not pass their screening?
 - What is the method for making that referral and is it consistent across the state?
 - Is help with travel to appointments available consistently across the state?
 - Why do parents decline EA referrals?
 - What variables would need to be changed for offices providing screening only vs offices providing diagnostic hearing assessment (ABR, ASSR, etc)
 - These might be the same variables
 - Would variables need to be different for medically/clinically based practices vs. educational practices?
 - Who is looking at the scores on clinic and what the numbers reflect?
 - What variables would be important for families?
 - What is the wait time for appointments?

- Would a quarterly report be useful so that clinics/agencies could react in a more timely manner
- Would this help families in choosing a facility to provide services for their child?
- Would this help families in choosing a facility to provide services for their child?
- Would this prevent families from engaging in Part C services if the audiology area of an AEA scored poorly?
- Is this feasible?
 - Are other clinics offering options of dx testing sites or consistently sending them to only one facility despite wait time for appointments?
 - Do parents know that there are other options available for more timely services?
 - Do we need to look at training PCPs first since they are often referring children for outpatient screening and diagnostic testing?
 - ENT facilities vs. dx testing facilities
 - Is more training needed with birth facilities so that they are not referring to the wrong types of facilities?
 - Question from Teresa Hobbs: Any data available on families that don't speak English, specifically Spanish? Sioux City has a large need as there are 44 different languages spoken in their AEA region. Is this something that EHDI can pull from data? How many D/HH children are not English as their first language? Is this something that can be pulled from the ACHIEVE system?
 - Part of our HRSA grant does focus on how are we equitability serving our population, but we will see if/how this can addressed in our data

Work Groups Update and Assignment Reminders (Linda)

Reminder of past workgroups and what was being discussed. Due to time constraints and membership attendance, the meeting was adjourned following the subcommittee discussion and reminders.

- **1-3-6 Subcommittee** (request they work on audiology quarterly reports – format, what type of things needed, feasibility) – Linda take notes
 - Stephanie Childers, Mariah Jarosh, Julie Jeon, Lisa Anderson, Tonya Krueger, Megan Palmer, AAP Chapter Champion
- **Family Support Subcommittee** (previous work in the area of accessibility, consideration of videos for families and brainstorming family outreach via community events)
 - Tori Carsrud, Savannah Hobbs, Deaf Advocate, Teresa Hobbs, Heather Dirks, Tina Caloud, Parent Advocate – Heather Take Notes
- **Education and Outreach Subcommittee** (previous work in the area of short Youtube Videos to possibly see successful adults that are using various forms of communication or parents thinking about communication options for their child)
 - Susan Brennan, Monica Stone, Rita Fredericks, John Cool, Annette Hyde, Elizabeth Woods, Michelle Vacarro – Rita take notes

Meeting dates for 2024: April 11, 2024; July 11, 2024