

MEETING AGENDA			
DIVISION	Public Health		
MEETING TITLE	April EHDI Advisory Committe	ee Meeting	
FACILITATOR	Tammy O'Hollearn		
DATE	4/10/2025	TIME	10:00 a.m. – 12:30p.m.
LOCATION	Zoom Meeting Link: <u>https://w</u> Meeting ID: 161 250 9542	ww.zoomgo	ov.com/j/1612509542
MEETING PURPOSE			
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- Jennifer Proctor Representing TDHH
- Tammy O'Hollearn Iowa EHDI Director
- Heather Dirks EHDI Family Support Coordinator/EHDI Follow-up Coordinator
- Linda True EHDI Follow-up Coordinator/Audiology **Technical Support**
- Amber Tucker Interpreter
- Danja Hirsch Interpreter
- Stephanie Childers Representing Educational Audiologists
- Annette Hyde Representing AEA Special Education Directors
- Kristen Moriarty, DO Representing Iowa Academy of Family Physicians
- Jenni Macke Representing Birthing Hospitals, Rural Hospitals
- Tina Caloud Iowa School for the Deaf, Deaf Education and Advocacy
- Tonya Krueger Iowa Specialty Clinics Children with Special Healthcare needs
- Tori Carsrud Representing Department of Education --Statewide Hearing Consult
- Megan Palmer Representing Pediatric Audiology •



- Joni Boone Iowa Hands & Voices
- Lisa Anderson Representing Speech/Language Pathologists and AVT
- Nicole Stoecken, DO Representing Iowa AAP Chapter
- Hailey Boudreau EHDI Program Supervisor
- Chantelle Broome Parent Advocate
- Toby Yak EHDI program epidemiologist
- Vania Kassouf Children's Deaf Advocate, Deaf **Community Member**
- Tashina Hornaday Representing Iowa Medicaid, Hawk-I
- Susan Brennan Iowa DB Project Director, ISEVBI Director
- Michelle Vaccaro Parent Advocate

EHDI Advisory Committee Member Departure:

- Liz Woods TDHH from Heartland AEA departed
- Jennifer Proctor will be filling this role. Jennifer works at Heartland AEA as a TDHH.

EHDI Personnel Updates:

- Heather Dirks has been hired as a full-time employee
- This is a shared position with EHDI and the Iowa Deafblind Project for family support

CDC Cooperative Partnership Update:

- Submitted competitive application 3/4/2025.
- Submitted 2 days early.
- As of Tuesday, 4-2-2025 all EHDI staff were dismissed from CDC, except for Erika Odom.
- Funding through June 30, 2025, and new grant funding is not set to begin until July 1, 2025.

HRSA Grant Update:

- Notified in March 2024 that Iowa EHDI had received 42% of HRSA funding, and the program will hopefully receive the rest later.
- Last year funding also came to the Iowa EHDI program divided and Iowa EHDI received the full before the end of the fiscal year.
- Reception of the rest of the funds will depend on US Congressional budget approval.

Hearing Aid & Audiological Services Update

There was a significant wait list last year, so funding was • all allocated by the end of August 2024.



	 A new waitlist has been started for 2025, and providers have done a good job of removing patients who have obtained funding from other sources. Currently, 7 on wait list with 10 outstanding claims, so in a holding patten for the rest of the current fiscal year (which ends June 30, 2025). From the last fiscal year, unused funds were allowed to be carried forward to the current fiscal year, so 1,330 were put towards this year's funding per legislative allocation approval. The EHDI director's paid time towards the program was adjusted, which allowed an additional \$3100 to go towards the funds. Traditionally \$156,000 has been allocated annually for the Hearing Aid and Audiological Services Program. The program is awaiting budgetary approval for next year's funding, which could begin on July 1, 2025. Member Updates – None currently EHDI Program Updates: The EDHI Administrative Assistant has been working hard to update all documents and forms in our system. lowa EHDI can no longer use the Traditional EHDI logo or EHDI/HHS logo. If previously used documents/resources do not appear on EHDI/HHS logo. If it is not available on the website, EHDI can try to repost on the EHDI Pages of the HHS website. If it is not available on the website, EHDI can try to repost on the EHDI Pages of the HHS website.
10:30 - 10:45	AEA Hearing Screening Services (Annette):
	 Report from Annette Hyde: AEA Special Education Directors are working diligently with the Department of Ed to work through a variety of guidance documents. Responsibilities for AEAs and special education funding have changed due to legislation in HS 2612. They will be reducing their scope of work to fit within their funding and responsibilities within special education. There is also new guidance to interpret AEA responsibility, which can dictate how special education funding is used by AEAs. Funding is special education funding, and that can



dictate what educational audiologists and audiometrists are allowed to do related to hearing testing. Special education directors and DE administration want to make sure that they are appropriately using funds moving forward.

- Currently, decisions are being made in relation to school age students. It has been determined that AEAs will continue to do some whole grade level screening, but the number of grades and which grades are yet to be determined. Hearing Screening is seen as a safety net as a part of the <u>Child Find</u> effort.
- As far as Early Intervention is concerned, operation of the state's Early ACCESS program is provided through the Department of Education, with partnership agreements with signatory agencies HHS, Child Health Specialty Clinics and Department of Ed to operate Part C Early Intervention Services in Iowa. These entities have identified AEAs as the primary provider of 0-3 Part C Early Intervention services. AEAs hire the staff to run the EA program. MOU is still in place between HHS and DoE, which specifically addresses the activities surrounding EHDI. Currently, <u>AEA Special Education</u> Directors and DoE are working out the details of how they will be handling 0-3 hearing referrals as they come in. AEA Special Directors are committed to partnering with EHDI for this work.

Report from Tori Carsrud:

- Tori agreed with Annette's description of the current situation for funding and services in Iowa for 0-3.
- The focus is committed to how to spend special education funds so that they are staying within the current law.
- The DoE wants to focus on kids who are already identified with hearing loss and are looking at what are the approved steps forward to address needs.
- Tori identified Tammy O'Hollearn as a partner to this and indicated that DoE will continue to communicate with Tammy, especially in the area of finding other providers that can fill in gaps to hearing testing services.
- Details will be provided as they are addressed.
- Additional Training will be needed as this process roles out
- Tori indicated that if there is any 0-3 learner where someone has a concern, whether based on newborn, op or hearing screening alone, or any other concerns that a referral can be made.



Currently, neither Annette nor Tori can address what the referral process will look like (i.e. a hearing specific EA referral will be required or if that will be determined through the <u>EA referral process</u>).

Topic Discussion:

	Topic Discussion.
	(Question) Linda: Do you consider children who do not
	pass hearing screening to be a part of the Child-find
	process?
	 (Answer) Annette: AEAs do not have a standalone
	clinic for hearing screening, but that hearing
	screenings should be a part of the childfind process.
	 (Question) Linda: Will an EA referral be needed for every child who does not pass a newborn hearing screening?
	\circ (Answer) Annette: We are not sure about all of
	those details.
	 (Answer) Tori: We will take any referral for any
	need.
	(Question) Jennifer: [AEAs] will keep doing what we are
	doing for EA referrals, correct?
	o (Answer) Tori: Yes – [AEAs] will continue the
	current process for EA referrals.
	(Question) Linda: Will hearing screening with or without
	EA referral have a cost to families in the upcoming year?
	 (Answer) Annette: At this point they are not, but
	that does not mean that they will not in the future
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clarification questions regarding data have been discussed via email since those initial discussions. Tammy has responded to many questions to clarify need for diagnostic testing throughout lowa.

- Dr. Curtis and Marcus were able to communicate via email to discuss a pilot.
- <u>Wendell Johnson Speech and Hearing Center</u> audiologists have volunteered to provide unsedated ABR testing for babies in the EHDI SOC. Spoke with Julie Jeon, EHDI Advisory member, about piloting with audiology services with this program. WJSHC is ready to move forward with further discussions when the time comes. They plan to set aside designated times should we pilot this project.
- Tammy and Tonya spoke about two regional clinics where there may be capacity to pilot: Fort Dodge and Creston.
- EHDI staff will look at those areas to review needs of children in these areas, including where families need to travel further for diagnostic testing.
- EHDI staff will continue to look for additional diagnostic testing opportunities with facilities that serve children that might want to provide diagnostic audiology services, such as birthing facilities or audiology clinics not currently providing diagnostic ABR for infants.
- EHDI staff will continue working on moving this forward to explore tele-audiology as a partnering option. If there is a facility interested in partnering with EHDI on building diagnostic capacity, EHDI would pilot first to work through logistics, such as billing.

Topic Discussion:

	 (Question) Jenny Macke: For babies that do not pass outpatient screening, is the sheet of diagnostic centers still the current facilities for sending children? (Answer) Tammy: All AEAs have been removed, so the list is current. If there are changes to diagnostic facility availability, EHDI staff will let people know ASAP so that kids may be able to get into diagnostic testing in a timelier manner, especially if closer to the child's residence.
11:00 – 11:45	EHDI Family Support Activities (Heather): Background of family support activities – for children with a diagnosed hearing loss, EHDI Family Support sends out a parent packet. All families receive a packet that includes different resources and an updated parent guide, information about events,



and resources for parents, including Iowa Hands & Voices. The EHDI Family Support Coordinator then contacts the family by phone/text. The EHDI Family Support Coordinator ensures EA has been discussed. If the family has not had a previously referral, EHDI family support then either makes an EA referral or marks the family as "declined" and will triage family's needs. Some families need support finding funding, some just like another family or deaf partner to talk to.

Two types of mentoring services: Family-to-Family Partners and Deaf/HOH Partners. Families can connect to either or both supports. There is also a monthly book club, which offers a different book each month. During the book club meeting, a book is read via ASL by a deaf adult. Family event offerings include inperson events, family events in collaboration with other agencies (i.e., H&V, ISD and ISD family support mentoring program). There is also a program called "New-to-the-Journey" which is a web-based meeting for families for different topics and resources. During these events, families have the opportunity to talk to each other and/or an expert regarding a topic of concern for families with hearing loss.

Upcoming Family Support Events:

- 19 families registered for tonight's New to the Journey Open to children of all ages
- April 26, collaboration with ISD Family Mentoring Program 4-6:30 Bowling event at Warrior Lanes in Waukee
- April 26 Book Club
- Next New to the Journey will be in May: Fathers Panel. Fathers and Grandfathers talk about their children who are D/HH and experiences. This event will be held on May 19, 2025 at 7:00pm. EHDI Family support is currently looking for fathers to share their experiences.
- Currently, EHDI Family support is collaborating with ISD Family Support for possible monthly events in different areas of Iowa.
 - Next event will be in June 2025 for a family swimming event in Burlington. Details to come.
 - In the works: Summer Park Play date, details to come
 - Also working on pilot program for baby-toddler groups that collaborate with libraries across the state for story-time and family conversations
- Newsletter: Upcoming events, resources, book of the month with a child DHH



- 207 families that subscribe and a handful of professionals
- Sent monthly
- Please send Heather any upcoming events --Outgoing communication must go through our administration and COMMS, so please send as soon as you know about it so we can get it out in a timely manner
- Try to work on newsletter about a month ahead of time.

Updates on Family Partners Program:

- Started March/April 2022 •
- In 2022, 20 family-to-family partners were matched with families with recently diagnosed children with hearing differences.
- The number of families in the program has remained steady since for families with children ages 0-3 with identified hearing loss
- 2023: 11 additional families matched
- 2024: 12 additional families matched
- 2025: we have currently 4 families matched since the beginning of the year
- Have had 47 families in total since inception in 2022

Updates on DHH Partner Program:

- 2022 -- 11 families matched
- 2023 12 families matched
- 2024 9 families matched
- 2025 5 families matched

EHDIs DHH Partner program has been working with the new ISD Deaf Mentoring Program, with was formed with funding from Iowa's LEAD-K law. The contracts with ISD for Deaf Mentors are in place, so EHDI will begin collaboration with the ISD Deaf Mentoring Program and transition to ISD. This will allow more opportunities to meet with the mentor and in-person home visits. Tina Caloud – No additions to Heather's report.

EHDI Family Support Needs Survey:

- 187 surveys sent
- 57 responses, about 30% response rate.
- Asked how families liked to receive information:
 - 1. Email
 - 2. Text
 - 3. Snail Mail



- Asked top 3 topics interest in:
 - 1. Resources in Iowa 63%
 - 2. Advocacy
 - 3. IEP and 504 transition to schools age (current NTTJ)
- Asked top 3 resources or supports do you use the most: •
 - 1. EHDI Family support newsletter
 - 2. Events to socialize
 - 3. Book Club/Family Partners
- Asked if families have attended a virtual event:
 - 70% said "No" giving the following reasons:
 - Conflicts/timing
 - Attention to emails.
 - Baby very young for virtual event,
 - Other activities
 - Don't want to be on computer at home outside of work
- Asked if families have attended in person event
 - 71% reported they have not attended due to:
 - Scheduling/time,
 - Young child,
 - Location of events,
 - Child with special needs/hard to get out of house with medical needs
 - . Illness
- Asked what times or days work best for virtual events:
 - Saturday mornings
 - T/TH evenings.

**Virtual events are currently offered on Saturday mornings and T/TH evening, but we will continue to monitor family preference for timing.

- Asked if family has connected with EHDI Family-to-Family (FF) Partner or Deaf/Hard-of-Hearing (D/HOH) Partner:
 - 58% had not connected with an EHDI Family Partner or Deaf Partner.
 - 25% have connected to a FF Partner.
 - 15% D/HOH partner.
 - Top Responses for not connecting to EHDI Family Support Partners:
 - Unsure/No Reason
 - Had one at the beginning but hearing wasn't the biggest concern
 - Still waiting to complete audiologic "work-up,"
 - Want to revisit EHDI Family Support when child is older.
 - Support and resources from EA and PCP.
 - New to the DHH community,



 What to change that would make EHDI Family Support Partners more useful to families: Finding time to meet Knowing more people in the area/community What did you like about EHDI Family Support Partners: Connecting virtually was helpful. Helped with formulating questions, Learned about accommodations in school, Learned how to advocate for [child]. Great talking to another parent and DHH partner to understand what things they have gone through Asked what activities families would like to see for upcoming EHDI Family Support Events: Social events like the Animal Rescue League event, • Children's museum. • **Zoo**. • Story time, • Play groups, o Crafts. Family and disability friendly events, • ASL activities, • Picnics. • Parent coffee chats,

Unable to find time.

- Outside events
- Asked what additional resources families would like through EHDI Family Support:
 - Information about sign language support,
 - Connecting with other HOH children,
 - More in-person events,
 - Newsletter tips and tricks,
 - Information about financial support,
 - Legislative news that impacts DHH community
- Open Feedback from Family Needs Survey:
 - Requested more local events
 - Thankful for the programs,
 - Families like newsletter information.
 - Appreciated connection to resources,
 - Liked variety of activities to be offered,
 - Thankful for providing families with opportunities for funding resources
 - Families were connected to EA,
 - Appreciate financial resources,
 - Liked Deaf Partners program



	 EHDI was able to offer families Walmart Gift cards to respond to the survey. Families cannot use gift cards for certain things such as alcohol, tobacco and guns. EHDI had gift cards left over from a previous survey and were able to offer families a gift card for their response feedback to the family Support Needs Survey. Heather linked new Parent Guide in the meeting chat: Work done on this with a UIHC student as a part of their capstone project. This will be available in Spanish as well.
	 This will be available in Spanish as well. Requested advisory member input Will link to EHDI Family Support Web Pages on HHS Website when finalized.
	Upcoming Resources:
	Family Transition Packet
	 EHDI Family support will be starting to contact families as they are aging out of Part C, so that families know where to obtain resources.
	 Using QR codes to link to other programs, such as DE and H&V or ISD. This will also help them get a free book through
	 H&V regarding this. H&V applied for a grant through Prairie Meadows, so this is pending approval.
	 Also working on an "about me" page for families to work on together to send on the first day of school.
11:45 – 12:00	Provider Education Topics (Linda)
	 Beth Walker did a session on mild hearing loss and guidelines for services and support for those families even with a mild hearing loss and language acquisition. Other upcoming provider learning offerings: Best practices for hearing screening (Date TBD) April 23, 2025: Unilateral loss and single sided deafness with Tanya Van Voorst, Au.D May 21, 2025: Refresher for Birthing Hospitals on INSIS Reporting with Tammy O'Hollearn and Jini Cox May 29, 2025: cCMV Provider and Parent Education with Julie Jeon, Ph.D and UIHC Au.D
	Candidates
	Contact EHDI Staff with Provider Education Topical Ideas

IO WA	Health and Human Services
	Link to <u>Provider Calendar of Events</u> for upcoming and past presentations
12:00 - 12:30	Diagnostic Audiology Quality Assurance Reports (Linda/Tammy)
	Quality Assurance Quarterly Reports have been an ongoing topic and have been worked on through the EHDI Advisory committee, beginning with an initial topic discussion in April 2023. Preliminary discussion led to a subgroup committee of audiologists on the EHDI Advisory committee. In April 2024, the audiologist subcommittee discussed feasibility and evidence based best practices that could be monitored for diagnostic audiology centers throughout the state. Audiologists in the subcommittee group discussions were Megan Palmer, Stephanie Childers, Julie Jeon, and Linda True. All audiology subcommittee members have experience in pediatric diagnostic testing for the 0- 3 age-group in Iowa across multiple settings: Medical, Educational, University. It should be noted that an email communication was sent out to all pediatric and educational audiologists who could be impacted following the April 2024 meeting. No audiologists outside of those serving on the EHDI advisory committee responded to the call to discuss this topic or best practice areas that should be monitored for quality assurance. Currently, there are 8 diagnostic centers in Iowa who will be receiving quarterly QA reports. EHDI will not be sending QA Quarterly reports to the 8 diagnostic centers in surrounding states where Iowa children are regularly referred for diagnostic assessment. The 6 areas that will be monitored were discussed with EHDI Advisory audiologists, as well as the evidence supporting these best practice areas:
	 Diagnostic testing by 3 months of age (HRSA Mandate) Referral to Part C EI Program or documentation of parent decline within the recommended time period following diagnosis. JCIH defines this as between 2-7 days. Reporting to the results within the EHDI INSIS database within 6 business days (lowa Law) Repetition of Outpatient Screening prior to diagnostic ABR assessment (only one OP screening should be done according to JCIH) Number of NYD Outcomes prior to a diagnostic confirmation of type of permanent hearing loss, transient loss, or normal hearing (JCIH and Published Audiology Literature) Number of Days between first diagnostic ABR session and confirmation of ABR to exceed timeline greater than 3

IO WA	Health and Human Services
	months of age, per JCIH recommendations (**Note: This metric will not be sent with initial reports due to variability in reporting. EHDI will continue to look at this metric for feasibility of reporting in the future).
	Search reports for these metrics have been finalized by Linda and Tammy using information in the INSIS database. Currently, EHDI staff are finishing the development of the report layout and then will be in contact with an audiologic facility to pilot the reports. The pilot facility will also give the EHDI staff feedback on the layout and readability of both the report and instructions. Tammy will be sending out additional information for diagnostic centers who will be impacted when report creation is finalized. A copy of the QA Audiology Report metrics will be available upon finalization of the updated EHDI Best practices manual.
12:30	There were no advisory committee member questions. Closing, Next Meeting Topics:
12.00	 Annette reported that she hopes that she and Tori will have more confirmation of what hearing services will look like for the 0-3 population. Susan Brennan will talk with Sarah about possible discussion updates from the DB Project, including current number of children on the current DB Project Roster. Linda will update the status of the Diagnostic Audiology Facility QA Reports. Tammy will give funding/CDC updates and any changes that may occur within the department and HHS. Also, will discuss services that may change with legislative updates.
	Thank you to the interpreters.

Notice of cancellation for any special accommodations needed to participate in this meeting must be made no less than 72 hours in advance of the meeting

Upcoming meeting dates for 2025: July 10, and October 9



EHDI Prog	ıram Staff
Jinifer Cox	Heather Dirks
EHDI Administrative Assistant	Family Support Coordinator
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Services	Services
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Linda True Follow-Up Coordinator/Audiology Technical Support Iowa Department of Health and Human Services Lucas State Office Building, 5 th Floor 321 East 12th Street Des Moines, IA 50319-0075 515) 204-6948 – Direct (833) 496-8040 – Toll Free <u>linda.true@hhs.iowa.gov</u>	