

Early Hearing Detection and Intervention (EHDI) Advisory Committee Agenda

Thursday, April 14, 2022

Membership Present: Linda True, Karen Thompson, Michelle Vaccaro, Barb Carlin, Annette Hyde, Tori Corsrud, Liz Woods, Dr. Krishna, Sarah Johnson, Diana Hanson, Emmi Goetz, Teresa Hobbs, Stephanie Childers, Tina Caloud, and Tonya Krueger

EHDI Staff Present: Tammy O'Hollearn, Amanda Hagerman, Rita Fredericks and Heather Dirks

Welcome, Introductions & Announcements

Committee members introduced themselves and who they represent on the committee. Annette shared AEA's and school districts were going live with the new Department of Education database, ACHIEVE, Friday, April 8, 2022. They are starting with the 0-3 population. They will then roll it out for the Individualized Education Plan side for children over 3 beginning in May. All schools/AEAs will be enrolled by December 1. Rita asked if there would be a parent portal and Annette confirmed that would roll out in the fall. Parents will have the ability to review documents.

EHDI Personnel Updates

Tammy reported Joy Barlean had decided to step down in her role as family support coordinator the first part of December. Heather Dirks was hired and began on January 31, 2022. Heather also works part-time for the DeafBlind Project! Tammy also reported Shalome Musignac-Jordan's last day was February 8, 2022. The EHDI team just finished interviewing for that position and made an offer. They will announce the person that will be fulfilling that role beginning mid-May through email.

AAP Chapter Champion

Tammy announced that they finally had a new EHDI American Academy of Pediatrics (AAP) Chapter Champion, Dr. Krishna. Dr. Krishna works at UnityPoint Health in Waterloo. Tammy said that she worked with Dr. Krishna on a quality improvement project and she was very invested in children and families and has great connections in her community.

Hearing Aid and Audiological Services Funding

Tammy provided an update on the bill brought forward this year to have insurance companies cover the cost of hearing aids for children (HF 2568). Tammy shared that they did hold a couple subcommittee meetings. Some parents and children came and testified, including an audiologist/speech language pathologist from the University of Iowa. Tammy reported that the bill was modified removing the insurance company requirement. They modified the bill to include the ability to roll over the funding from one year to the next to decrease the numbers of families put on wait lists. Tammy explained that even if the funding can be carried over, they still cannot allocate more funding than what was appropriated. She said it may help ensure a little more of the funding is not remaining due to the time to process, etc. Tammy also reported that the legislature added a sentence the last bill she saw which will not allow the IDPH EHDI program to contract with a third party. The third party the program has used since inception is North Iowa Community Action Organization who has been getting children enrolled and processing claims since 2008. The third party statement was added when a parent brought up the funding that was going to them in a contract. Tammy explained that this entity works with the family to gather the needed information and

for those that do not qualify, they often share other resources. They also work with the audiologists to gather estimates so the program can keep enrolling children so long as the money is not allocated. They have experience with CPT codes, insurance payments, etc. Tammy said that is all experience and time the program does not have and would have to hire for and there is not funding to cover their current staffing needs. Tammy explained her staff do not have the time or expertise to do this so there will still be at least the same financial cost as it will take at least a half-time person, require a small database, etc. Tammy recommended due to the IDPH and Department of Human Services merger, that they consider having Medicaid manage this program since they understand insurance and have the infrastructure. She said if the IDPH EHDI has to take over, there will be lots of delays come July 1st. Payments will not be as timely and may require more paperwork, as well as the time to set up a new program, database and hire someone. She will keep committee members posted as this bill works its way through the legislative process.

Federal Grants Update

Tammy provided an update. She said they have been busy the last year with competing deadlines and many reports. The following is a brief overview of deadlines and information submitted. This does not include many other reports that are due, as well as the actual grant activities. There were 29 deadlines, not including grant activities, follow-up, etc. Only a few are mentioned below.

- Evaluation plan due to CDC in March 2021
- Individualized data file for occurrent births from 2020 – over 37,000 records with 179 variables due to CDC in October 2021
- HRSA EHDI Grant – December 2021
- CDC aggregate data file for 2020 occurrent births – January 2022
- CDC EHDI Grant – March 2022
- CDC EHDI Evaluation – March 2022
- National EHDI Meeting – March 2022
- Diversity and Inclusion Plan to HRSA – April 2022
- Resubmission of individualized data file for occurrent births from 2020 – over 37,000 records with 179 variables due to CDC in May 2022

Tammy noted that she has also attended several meetings and asked for meetings with CDC to discuss their data definitions and data dictionary as there are some areas that states are submitting the data differently.

Tammy said that all states were not given their full funding due to congress not passing a budget until recently so awaiting a new notice of award to restore full funding from HRSA.

Iowa's evaluation was on the EHDI data system and the ability to easily produce reports or data for CDC reporting. She shared that they will share the evaluation results with the OZ team, as well as the OZ Systems User Workgroup to look for developmental areas to make the process easier!

EHDI Facebook Page

A notable accomplishment for EHDI family support to get approval from the Department of Public Health leadership to have two official Facebook pages for the EHDI program: a public page to provide information to the general public and a private page for parents to join. The approval is for a pilot for six months. At the end of the

six months, the program will share the analytics and feedback from users to see if leadership will continue to support the page. The purpose of the Facebook page is for education and outreach to families, as well as providers. It is a way for the program to engage families that may otherwise be harder to reach and share resources.

Provider and Family Training Calendars

EHDI personnel developed two new training calendars. There is one for parents and one for providers. They list the upcoming trainings, a link to register or attend the trainings and they are both on the EHDI website either under the [parents page](#) or [providers page](#). That is also where the PowerPoints are posted and link to YouTube for those presentations that can be recorded.

Tammy shared that Iowa won website of the year in 2016. This year, they won [website](#) of the year again for EHDI programs who have already won that are still doing a great job of providing resourceful websites for families. These awards are voted on by a group of 20-25 parents that review all EHDI program websites! Tammy said it remains to be seen what changes will be made to the websites upon the merger, but they are thankful for the recognition!

Audiology TA Update

Diana Hanson reported that she and Emmi continue to support the EHDI program through audiology technical assistance. Technical assistance may be to staff with questions about follow-up for a child, recommended audiology best practices, and so on. Additionally, she and Emmi continue to review diagnostic hearing assessments completed by Area Education Agency audiology personnel. Diana said that has slowed some so she thinks that the AEA audiologists are more comfortable completing this process. She said they may need to put out a reminder they are available to assist with any questions or interpretation moving forward. Diana and Emmi continue to enter out of state diagnostic assessment forms for audiology clinics like Boys Town or providers in South Dakota who may be diagnosing Iowa infants. The last thing they have been working on is revisions to the diagnostic protocol.

Quality Improvement Update

Amanda reported that she is in the process of analyzing two more years' worth of data. She will present the findings on Thursday, April 21st. At that time Amanda will review how well Iowa is doing with meeting the national 1-3-6 goals, improving timely diagnosis and decreasing lost to follow-up throughout the hearing healthcare process.

Amanda also discussed how the EHDI program is turning data into action. The EHDI team has worked with a number of audiology clinics and birthing facilities where there are larger numbers of children being lost or not served in a timely manner. She talked briefly about the process and noted that all providers had made progress since the EHDI team first met with them to review their data. Amanda explained that the team looks for small ways the provider can improve through a quality improvement task(s). She gave the example of one of the audiology clinics almost doubling the numbers of children being moved through their hearing healthcare journey and serving them in a timelier manner following the quality improvement project. The program started with providers in the Johnson and Linn county areas, but will be moving to central Iowa soon. Amanda explained that she reviews the populations whose data show they are being left behind and most at risk for late diagnosis or becoming lost. The providers have been asked to provide additional assistance to these individuals in a variety of ways and not use a one size fits all approach. She explained that some families may need more assistance with

scheduling or the lack of resources or timing may be getting in the way of the appointment and so on. The EHDI team made sure a parent was also included in the quality improvement efforts to provide a parent perspective, share resources they are aware of that audiology clinics or hospitals may not have thought of and so on. Tammy noted that the efforts have been well received. The team looks at this effort as a partnership and they work to build upon clinic or hospital strengths and then use the data to show progress or areas for continued improvement. Teresa inquired who some of the communities identified. Amanda said that the program started with Johnson and Black Hawk. Next will be Linn County, Dubuque and Polk County.

Amanda shared that the program will also be looking for qualitative data in the areas where parents are being left behind the most. Initially the focus will be on the BIPOC community. However, Amanda noted that you really have to break down the communities throughout the state and not just look at the state as a whole or you may miss some important groups who continue to be left behind, but you would not know that if you only looked at the aggregate data.

Early ACCESS Data Presentation & Discussion

Annette and Tori Corsrud put together data on Early ACCESS (EA) referrals and enrollment. They also compared referrals for DHH children to overall referrals to EA for all children who qualify for EA to see how populations compared overall. Annette noted that they wanted to learn from this and see if there were areas they need to work to improve upon. See the attached PowerPoint for the presentation. Please note that data was updated in a couple of areas following the presentation to ensure it was accurately portrayed. Below are questions and responses that came up during the presentation.

Annette said they compared EA referrals with referrals for DHH to see how they were doing overall. Goal is to help families learn and support their children with growth and development. AEAs are primary providers of the services. Other agencies provide referrals and sometimes support. They started with the EHDI data first. Annette reported that referrals come from a large variety of people, including families, providers, EHDI, CPS, DHS and childcare providers. Looking at all children referred to EA, primary is medical, parents, and DHS the larger amount of referrals. Looking at DHH referrals, the number of referral is largest from providers at 43%. Parents also refer and LEA, AEA as well. She shared they expect referrals from all of these locations and noted that 50% of referrals occurred before 6 months for DHH kids.

Service data showed that of those children referred, 41% end up on an IFSP whereas 67% of DHH infants end up on IFSP. They decided to look at that number because DHH is an automatic qualifier for EA. She noted that half of the case closures were due to parents declining service. Twelve percent is families who withdrew consent for services, 28% moved or they were unable to locate the family prior to services beginning and 9% DHH kids were determined not eligible. Annette noted that they all should have been eligible because it is an automatic qualifier when a child is DHH so they found those kids records and reviewed their paperwork. She noted on three occasions it was due to staff misunderstanding so they retrained the staff. The others, they did not have the paperwork showing a hearing loss. They then explored said they may need to look at what the first contact looks like because so many families are declining support. She said they are looking at finding a way to offer the service or support at later time to see if the family changes their mind. Tammy asked if the data was for the initial referral. She said that they sometimes learn families were referred, but then declined or didn't respond, but then EHDI refers them and they then enroll. Annette said some of those kids might be in there because they did not

pull that data out. Tori said this is the first referral for the kids so kids re-referred may not be captured in the chart reviews they did. Most common services were audiologists, TOD, and or SLP. DHH children had one of three or a combo and 84% were on IFSP. 16% of the children were on other or consult services only. Annette said that some AEAs use a primary service provider model where one person works with the family while other services providers consult. For example, a SPED teacher may be the primary provider and an audiologist or SLP may consult. Annette said they are looking to improve the system and collaborate with others. Most recently they are addressing situations of misunderstandings. They want to partner with DOE and IESBVI to look at all data and come up with areas to improve. Linda asked if AEA audiologists would be trained on putting data into the system when a child is enrolled and Annette said that should be easy enough. She said they would take that back to the task force and incorporate the suggestion.

Tina asked if the individuals reaching out to the parents are apologizing and saying their child failed, instead of reframing the outreach in a positive way. Consultation with the family regarding results may impact a parent's decision to proceed with Early ACCESS services and family support. Stephanie said that they are using out a reduction in hearing not hearing loss at Mississippi Bend AEA. She said changing wording seems to help. We try to not overwhelm parents but be supportive in any way that we can. Annette agreed that a larger-scale conversation about wording would be appropriate to take to back as a project for the council. They may create a short webinar that all EA providers have access to as a learning opportunity about language used when speaking to families. Tonya said they can have that webinar be available to providers and others working with families. Linda shared that audiologists are learning how to reframe language, and talking about reduction in hearing vs. hearing loss. This can help the conversation reflect how language learning may need to process differently from typically hearing children. She said they typically then talk about family support through the variety of providers, including deaf mentors. She shared that it is important to remember that EA services can help coordinate services for families that they do not provide.

Amanda asked when parents decline, do you have data on providers type? She asked because Hispanic and Latinx communities sometimes fear seeking healthcare or services and may not answer calls. She noted that Cedar Rapids has a lot of families that speak Swahili and French so are their interpreters helping in those situations? If there is low enrollment, refusals or a lack of response, it may be for reasons such as fear of government, lack of understanding, etc.

Diana commented that it would be so helpful to know which families they referred are declining. Dispensing pediatric audiologists could reinforce what services and supports they may get if they know a family declined. She asked if they could get information about what is happening after a family is enrolled in EA? Tonya asked how often would they want an update? Diana suggested every 6 months so they know they participated and progress is being made or not. Tori said that they may not be able to share that information if they do not have an exchange of information. For families that decline, EA may not have completed that process, but if providers did this and sent it, they could. Linda suggested they use the EHDI system to make notes saying that family declined since they are required by law to report certain information into the system. If audiologists see that they can talk to family to see why they declined and/or re-refer them. Dr. Krishna asked, as providers can we get the information that they declined when we refer them? Annette said if the information is on the referral they can, but that rarely happens that they have a release with referral.

Barb asked if there are deaf mentors in EA. There are not at this time. Tammy shared that the EHDI programs offers Deaf and Parent Partners for children under three and Iowa Hands & Voices is working to re-establish some support for families of all DHH children. They would need referred. She shared that Heather calls all newly identified children and late onset children if we are aware of the diagnosis, but older children we are not involved with.

EHDI Family Support

Heather and Rita spoke about the various things they have been working on most recently. Heather reported that Book Club is going well. Tammy said that we have even had a parent on that needed Spanish interpretation while also providing ASL. The books and Deaf adults that will facilitate each book club have been identified through September. Had started to record some of these, but have now reached out to the Iowa School for the Deaf and are partnering with them to interpret the books so that parents can go back and watch these videos when teaching their children after the Book Club.

The New to the Journey group is not as popular. The group has had to be cancelled several times due to no one signing up. Heather, Rita and Michelle Vaccaro are working together to find the best format for that group. They have decided to work with experts to put together informational videos in advance of the group so that if it is cancelled the program is not wasting time of the provider should families not show up, while still providing the important information. May also be in a question/answer format depending on the topic. Also a way to send these out after the meeting to families that could not attend or to those that attended, but there was a lot of information to digest. This also allows for the presentation and yet still leaves over half the meeting for families to converse with one another or Heather and Rita and ask questions without having professionals there where they may be concerned to say things because of their presence.

Heather reported she is in the midst of reaching out to all families and offer Family and Deaf Partners. So far she has matched 7 Family to Family Partners and 4 Family to Deaf Partners. Currently, contacts are being made via Zoom, phone calls and email. Most support is sharing of resources and knowledge or supporting families where they are at. Heather noted that the program is looking to recruit more Family and Deaf Partners. Heather always attends the first introductory visit with the interpreter, deaf adult and parent and then leaves those visits to be worked out moving forward.

The family support program is also in the midst of searching for and creating training. Barb and Tina asked about using Ski-Hi. Tammy explained that there is no funding within the budget to support the Ski-Hi curriculum. She said it is very expensive, both initial and ongoing that is required. She said that the Ski-Hi program is very specific and they won't let you train the trainer. She said that program cannot support that many visits with families as we are reimbursing mentors for their visits with families at this time, as well as the interpretation needs for each visit. Barb asked committee members if there was funding available from other funding sources to support this effort. No one knew of any additional funding. Tammy suggested that if anyone knew of other good family support training curriculum to let Heather or her know.

Advisory Committee Meeting Format Change

Tammy asked committee members if they are ready to get back to meeting in person. She said she would like to get back to the structure of the meetings pre-COVID where the first part of the meeting was for presentations and sharing of information, brainstorming, etc. and the second half for workgroups. Everyone on the call agreed that

they were ready to move back to that structure. Dr. Krishna said she may still need to be available via Zoom because of her clinic responsibilities. Tammy said that would be fine because it was important that she be able to participate. The meetings in July and October of this year will be back in person in the Des Moines area and from 10-3 p.m. Everyone in attendance on the call also thought three meetings per year were still sufficient.

Meeting dates for 2022: July 14 and October 13