

MEETING AGENDA

DIVISION	Public Health		
MEETING TITLE	October EHDl Advisory Committee Meeting		
FACILITATOR	Tammy O’Hollearn		
DATE	10/10/2024	TIME	10:00 a.m. – 3: 00 p.m.
LOCATION	Heartland Area Education Agency - Johnston REC - Conference Room 141		

MEETING PURPOSE

The Iowa EHDl Advisory Committee represents the interests of the people of Iowa in the development of programming that ensures the availability and access to quality hearing health care for Iowa children less than three years of age. The membership of the Advisory Committee shall be representative of stakeholders with an interest in and concern for newborn hearing screening and follow-up.

APPROXIMATE TIME

AGENDA TOPICS

10:00 – 10:30

Welcome, Introductions and Announcements

- Members Present:
 - Tori Carsrud – DoE/HOH Consult
 - Annette Hyde (Virtual) -- AEA Special Education Coordinators
 - Tashina Hornaday – Iowa Medicaid
 - Hailey Boudreau – HHS CCIC Section Supervisor
 - Chantel Broome – Parent Advocate
 - Tonya Kruger – Iowa Family Support Network
 - Megan Palmer – Private Audiologist/Mercy ENT - CR
 - Michelle Viccaro (Virtual) -- Parent Advocate
 - Kristen Moriarty, MD – Iowa Academy of Family Physicians
 - Joni Boone – Iowa Hands and Voices
 - Vania Kassouf
 - Sarah Harms (Representing DB Project for Susan Brennan)
 - Stephanie Childers – Educational Audiologists/MBAEA
 - Lisa Anderson, MS, CCC-SLP – Iowa Ear Center
- New Member: Joni Boone, Representing Iowa Hands & Voices
- Members Absent:
 - Tina Caloud/Chris Kaftan -- ISD
 - Karen Thompson – ASK Resource Center
 - Jenni Macke – Birthing Hospitals
 - Susan McDonald – IAD/Deaf Advocate
 - Julie Jeon – ISHA Representative/WJSHC
- Interpreters Present:
 - Julia Lyttle
 - Amber Tucker

	<ul style="list-style-type: none"> • EHDI Staff /Supervisor Present: <ul style="list-style-type: none"> ○ Tammy O’Hollearn -- EHDI Director ○ Heather Dirks – Family Support Coordinator ○ Linda True – Follow-up Coordinator/Aud Tech Support ○ Hailey Boudreau – Screening & Management Section Supervisor • EHDI Advisory Committee Member Departure <ul style="list-style-type: none"> ○ Mariah Jarosh, Iowa ENT Center PLLC (Representing ENT Clinics) ○ Teresa Hobbs, NWAEA (Representing Early ACCESS) ○ Elizabeth Woods, Heartland AEA (Representing TDHH) • EHDI Personnel Updates/email addresses <ul style="list-style-type: none"> ○ HHS staff emails have updated <ul style="list-style-type: none"> ▪ EHDI Website Home Page ▪ EHDI Staff Contact Information • CDC Grant – Funded! <ul style="list-style-type: none"> ○ EHDI is an unfunded mandate through the state of Iowa ○ The current cooperative agreement cycle was to end in June 2024, with a new competitive grant due in March 2024, but CDC changed it to an additional year of funding. 2025 will be a competitive grant year ○ EHDI was awarded for the 5th year of funding in July 2024 ○ There is a new data analysis requirement for this year ○ It is forecasted that new CDC grant opportunity will be out December 2024 ○ Next grant cycle submission will be due March 2025 • Hearing Aid & Audiological Services Update <ul style="list-style-type: none"> ○ Notice sent that as of August 19th, funding is 100% allocated due to carryover from 2023 wait list. We anticipate we may be able to serve 3-5 more children on the wait list ○ Less than 10 children on the current wait list ○ Encourage families to work with private audiologists for other funding (i.e. children at home) • Member Updates <ul style="list-style-type: none"> ○ None
<p>10:30 – 10:45</p>	<p>EHDI Family Support (Heather) --</p> <ul style="list-style-type: none"> • Brief overview for new members about what family support looks like in Iowa <ul style="list-style-type: none"> ○ Parent Packets/Resources ○ Direct Parent Contact – phone/text to ensure that they are getting supports <ul style="list-style-type: none"> ▪ May include EA support ▪ Answer questions about funding ▪ Offer Family Support Programs • Parent-to-Parent – 40 have been matched, 3 ongoing

	<ul style="list-style-type: none"> • Deaf adult-to-Family – 28 have been matched, one ongoing • Note: Deaf/Hard-of-Hearing Mentors will be transitioning to ages 0-21 for Deaf Mentoring through the LEAD-K Bill. Housed under ISD • Book Club for Tots <ul style="list-style-type: none"> ○ Deaf Partner Support ○ Literacy Support ○ Reading Tips ○ 4-5 Families typical ○ Questions • New-to-the-Journey <ul style="list-style-type: none"> ○ Current Session Ask an Audiologist (10-8-2024) • Distribution List/Newsletter <ul style="list-style-type: none"> ○ 159 Families enrolled ○ Some TODDs • In Person Events <ul style="list-style-type: none"> ○ 10-19-2024 Pumpkin Patch <ul style="list-style-type: none"> ▪ Central Iowa, Urbandale ▪ Marion, IA ▪ 22 families attended ○ ARL Event possible with Michelle • Family Feedback <ul style="list-style-type: none"> ○ Topics <ul style="list-style-type: none"> ▪ Resources ▪ Technology and Safety Items ▪ Advocacy ▪ Play Groups ○ Activities in person looking at <ul style="list-style-type: none"> ▪ Zoo ○ Feedback about not attending <ul style="list-style-type: none"> ▪ Not sure child is ready/family is ready ▪ Travel ▪ Intimidating • Dr. Moriarty indicated that she would like a packet to review so that PCPs know what families are getting and can support that program. <ul style="list-style-type: none"> ○ EHDI staff sent a packet for Dr. Moriarty
<p>10:45 – 11:15</p>	<p>Dept of Ed – DHH Advisory Committee (Tori) --</p> <ul style="list-style-type: none"> • For the past 3 years, Tori has facilitated this Committee • Meet 2x per year • All things HOH birth-21 • Feedback related to any portion of education related to hearing differences • Next meeting is 10/18/2024 • Talking about data – who are the learners • Updates from ASK Resource and change in recommendations for the state • Family Portal Update (slides attached)

1. Tool found in ACHIEVE which will allow families access to special education documents (similar idea to a MyChart used by health systems)
2. Log in required to give access to families
3. Shandon Grundemeyer (facilitator for family portal)
4. Slide Deck – who can access, what does it provide
 - Eligible account holders – families with eligible learners
 - IDEA
 - What is a parent in special education?
 - Who are the learners in special education
 - Special education for learners 18-21
 - Who will not get access – DoE will not be giving proxy access, you must be someone with a child who has DHH designation in the system
5. What will access provide:
 - Real time access to records
 - Calendar for up coming meetings
 - View Only rights and no place to enter comments
 - IDEA parents can choose if they would like an account (families who do not have access to the internet/do not “trust” access to internet)
 - Families may not give consent for electronic communication, and they will still receive a hard copy of assessments/IEPs
 - Does NOT replace face-to-face meetings
 - Users cannot update existing documents
6. Where found
 - Email with directions for setting up the account
 - A place where this tool can be found on the ACHIEVE system
7. Why some families may use electronic communication or web/portal (see slide deck)
 - Some families want more data than is obtained with report cards – want to look at progress monitoring in between face-to-face meetings
8. How can families receive more information about the family web portal:
 - Videos will be created and shared out to families
 - List-Serves – Teams involved can help get
 - Getting Started Guide/User Guide
 - One to get into system
 - One within the system (table of contents/control-find)
 - Training Videos will be offered in English and ASL. Do not have information about other languages

- Questions about Family Portal:

1. Heather: Will drafts of IFSP/IEPs be in the system for parents to view?
 - Tori: Will ask Shannon to confirm
 - Shannon: IFSP/IEP documents can only be created within ACHIEVE (unless teams are manually typing notes in another platform). Families will only have access to draft documents if/when an IFSP/IEP team member actively "pushes" the draft to the portal. Drafts are not automatically available to families in the portal.
 - Annette: draft may not be in there unless the provider pushes it into the portal for family feedback
2. Will there be a place for families to sign the IEP for the date of implementation?
 - Tori: Not sure about that, will check with Shannon
 - Shannon: At this time, there is not a way for families to "approve" proposed services documented on the PWN. However, this sounds like a good enhancement for us to consider.
3. Chantel: When will this start
 - Do not have implementation date as of yet
 - Currently having AEAs validate email addresses and ensuring current IDEA parents
 - Process of validation to end December 2024, so cannot go live until after this process
 - Shannon: We are waiting on AEA Early ACCESS providers and IEP Facilitators to complete the family contact validation process. We expect to be able to launch by spring 2025 but I would not formally announce this. I am awaiting a formal/approved statement from the Director.
4. Tammy: Will parents be able to message team within the portal?
 - Tori's current understanding is there is no internal messaging allowed at this time. It is for viewing documents only. Will double check on this.
 - Shannon: No, there will not be a way to communicate with team members via the portal. Families will be encouraged

to continue communicating with their teams in the same ways they do today.

5. Vania: what other Information will be available for the database?
 - Tori: Different from the Database, so that will be talked about shortly

- [**ACHIEVE Family Portal Overview Script**](#)

AEA Services Update (Tori/Annette)

- Overview House File 2612
 - Change to AEA System:
 - 3 different departments
 - Gen Ed – educational services
 - Support for Teachers
 - Media Support
 - Assistive tech
 - Lending library loan throughout state
 - Vans system to relay to schools
 - Special Education Department (historically 75% resources)
 - Bill brought forward educational services and medical will have funds historically used for media services sent directly to school districts, and they can choose to use it for AEA services or not
 - 40% of money this year, next year ALL of the money goes to the districts and they can decide how to use that money.
 - Many school districts are short on funding and they need to decide where to best use those funds
 - In Special Ed, no changes to funding for 2024, except there was less money so that there could be a division of special education services so that the oversight would move from AEA's to the DoE both for special education in AEA's and schools
 - Next year, there will be a 10% cut in funding which will go directly to schools which may or may not have to be used for special education
 - Problems because contracts had been sent out
 - Statewide loss of 500 AEA staff members
 - Mostly retired (early) or resigned. Small amount of pick slips
 - Workforce issues, so cannot automatically filling positions
 - AEA's were told that there was "mission creep" and so trying to audit all things that are done to see if they are AEA responsibilities
 - Department of Education will be charged with oversight of SPED instead of AEA's
 - Having conversations about what are lawfully required and what is not required by law

- Every AEA will have a DE employed Director of SPED
- Where does Childfind start and stop with hearing
 - Leaning into the department to help find out what that looks like
 - DE employed director of special education
- Trying to ensure continued collaboration with partners, but cannot avoid that there have been changes
- Over the next year there may be changes to what AEAs can do with capacity or are allowed to do, and things may look different
- Specific to hearing
 - No decisions finalized
 - Possible changes to referral process
 - How do we help with this to # families saying yes to EA
 - Discussion for school age hearing testing
 - Class/grade wide screening may be provided at specific grade levels, but looking at what requirements are needed to be provided
 - No current Iowa Law specifies hearing screening for school aged children
- Linda: Timeline for OP screening to help tell provider partners
 - Annette: Diagnostic testing is no longer happening via AEAs
 - Annette: There will not be a gap in any changes, and EA, AEAs and EHDI will work together to ensure a smooth transition
 - Annette: I don't think it will be a "massive shift" in services
 - Tori: We want to be intentional for ramifications for this discussion, as birth-3 is different than children 3-21
 - Tori: We don't want to lose kids [childfind] and help meet 1-3-6 goals

DHH Database (Tori)

- Rolled out August 2024
- For professionals working with children 0-21
- Collecting information about language acquisition for EHDI
- LEAD-K bill: requires annual report for language progress for children 0-8 if an approved language assessment is given (see below)
- Database also being used to collect diagnostic tests from audiologists
 - Can enter data and generate a report
 - Allows scheduling for sound booth appts
 - Keeps track of family scheduling

- If family shows, is rescheduled, cancels or no-show
 - COMPLETELY SEPARATE TOOL FROM ACHIEVE
 - Keeps track of all audiologic testing and language assessment
 - Teams have the ability to go back to July 1 and retroactively enter from this fiscal year
 - Contains all learner information for DHH students regardless of if they have an individualized services plan or not (regardless of IEP/IFSP status)
 - Assessments
 - Screening
 - Additional tests (i.e. functional testing, etc.)
- Learners found from a school or being seen in a sound booth and Early ACCESS are added
 - Gives a dashboard on child
 - Can add any language assessment that has been provided
 - II language assessments approved for EA
 - Drop Down Menu
 - Some for Auditory Users, Some for ASL users, some for multiple disabilities or combined communicators
 - Can choose one of II to report on, but if they choose a different protocol, does not need to be reported in DHH database. Approved list of Language Assessments by Iowa DoE:
 - [AEPS-3](#)
 - [ASL-EST](#)
 - [ASL-RST](#)
 - [CELF-5](#)
 - [Communication Matrix](#)
 - [DAYC-2](#)
 - [Kendall P-Levels](#)
 - [PLS-5](#)
 - [REEL-4](#)
 - [SKI*HI*](#)
 - [VCSL](#)
 - Law requires teams to enter scores if I of II was used and child is between 0-8 years old
 - The database allows the language assessment information to be entered through age 21
 - i.e. communication matrix might be used throughout entire educational career
 - Allows provider to identify if assessment offered but parents decline assessment (still family choice)
 - Allows provider to pull a report that shows how many learners scored average, above average, or below average, and what age range they are.

- After results are shared, DHH Consultant will have a report
 - How many HOH Learners scored at normed average, below or how many are independent learners
 - Law requires and annual report to educators
- 3/5 years in the making, and this is one portion that will have information
- EHDI grantors are asking for this
- Team may decide that assessment is not needed.
- Teams have the ability to go back to July 1 and retroactively enter from this fiscal year
- Currently audiologists and TDHHS have been trained
 - Next up SLPs
 - OTs/PTs
 - EA partners
- Question:
 - Vania – EHDI screening only so how is this different?
 - Tammy – EHDI is focused on screening, rescreening, dx information, including EA and Family Support as required by law and grants
 - Tori -- this database is different, it is an education focused database
 - Audiologists have access to both systems and are the link to both systems
 - Audiologists can be part of both medical and IFSP teams
 - Vania – how does the education system get this information?
 - Audiologists would need to enter data both into EHDI system and into this system at this time
 - Vania: Have there been cuts to mentoring services to the AEAs, especially 3-6?
 - Tori reports that she is unaware of any cuts to mentoring services
 - Annette reports that FEP program is no longer with the AEA, but there is a contract with ASK resource center
 - Heather: EHDI offers DHH Mentors, but working with ISD and DoE for birth-21 DHH Mentoring services
 - Dr. Moriarty: Who has access?
 - Right now, educational audiologists, educational audiometrists and school nurses
 - Administrators through read only
 - Districts can pull reports to help make decisions on employees for needs assessing
 - Not open to families currently, but meant for families in the future to access additional data

	<ul style="list-style-type: none"> ○ Are given language assessment outside of HOH be entered into this database? <ul style="list-style-type: none"> ▪ Not unless they have a hearing loss ○ Joanie: If a family declines language assessment, are there regular follow-ups to ensure that family might get assessment later on if they decide they want it? <ul style="list-style-type: none"> ▪ Tori: Would depend on if children still enrolled in EA support or if they have declined the enrollment again. ▪ Tanya: Would need a full assessment even if a child automatically qualifies for a reason, so they would still need a full assessment upon enrollment ○ Tammy: this would be all children who were D/HH, Deaf-plus or DB ● Will be keeping track of learner devices ● Will be keeping track of all audiologic and audiometric screenings ● Also shows the work educational audiologists are doing ● Possibilities about workload will change as this develops over time <ul style="list-style-type: none"> ○ Heather: How easy is it to enter data on a student that enters in from other state <ul style="list-style-type: none"> ▪ Tori: would need to upload all data as PDFs, there is no incoming state-to-state directly ▪ Stephanie – easy to connect throughout the state
<p>11:15 – 11:30</p>	<p>DeafBlind Project Update (Sarah Harms for Susan Brennan)</p> <ul style="list-style-type: none"> ● Serves children 0-21 with combined vision and hearing needs ● Services through families and team members through the educational system ● Summer Symposium – 2 virtual days and in person <ul style="list-style-type: none"> ○ Nancy Steele (speaker) – Communication Matrix <ul style="list-style-type: none"> ▪ Build with IEP teams communication matrix for a student in their school ○ 8 teams attended <ul style="list-style-type: none"> ▪ Nancy will be following up with all teams ○ Looking at similar format to next year’s summer symposium ○ Teams reported via survey responses positive feedback about applying the learning with students they are working with. ● DB Registry <ul style="list-style-type: none"> ○ 2023: 113 students on the registry ○ DBAC meeting next week ○ Current added 25-26 kids (up to 138 from December 2023 – October 2024)

	<ul style="list-style-type: none"> ○ Working with EHDI Family Support to get children to DB project and on registry early <ul style="list-style-type: none"> ▪ There have been several new children referred in the birth-three age range ○ Upcoming Events 0-21 <ul style="list-style-type: none"> ▪ Family Event – Iowa <ul style="list-style-type: none"> • October 20, Iowa Arboretum in Madrid, Iowa • 3 currently signed up (need 4) ▪ Behavior Guided Power Hour <ul style="list-style-type: none"> • Put on by Lynn McCallister and Emily Weave from Texas School for the Blind and Visually Impaired (TSVBI) • Two Sessions <ul style="list-style-type: none"> ○ October 24, 2024 @ 4:00pm ○ November 7, 2024 @ 4:00pm • May role over into symposium so that it can be both for educators, teams and parents • Current enrollment is 41 participants • These sessions are open to all who would like to attend • Registration closes next week (week of October 14, 2024) ▪ Open Hands/Open Access (OHOA) course for paraprofessionals only <ul style="list-style-type: none"> • Provided \$100 stipend for each module • Would really like to get paras this information and had 15 paraprofessionals • Putting on another from end of October to end of December, with Judy Gibson through MBAEA facilitating • In Iowa, Interveners are not recognized, so trying to get paraprofessionals trained to work with DB students • Biggest feedback from paras was that modules seemed outdated, but NCBD coming out with new paraprofessional modules, so hoping we can piggy-back on these to update OHOA modules
<p>11:30 – 12:30</p>	<p>Lunch (On Your Own)</p>
<p>12:30 – 12:45</p>	<p>Provider Education Topics (Linda)</p> <ul style="list-style-type: none"> • ENT, Birthing facilities, Audiology, PCPs • Typically hold webinars 6 times per year with different topics. • The last couple of years we have surveyed attendees what topics they would like covered. <ul style="list-style-type: none"> ○ Previous/recent topics included:

	<ul style="list-style-type: none"> ▪ Brain imaging and how it correlates with hearing loss, along with how the brain development for DHH children can look different from typically hearing peers; ▪ Parent questions about what is needed for CI process. ▪ Implementing a parent story in each provider webinar to talk about the lived experience portion of that topic as well. ○ Other topic ideas from recent provider surveys include: <ul style="list-style-type: none"> ▪ Unilateral hearing differences <ul style="list-style-type: none"> • brain development • language development impacts, • technologies that might accompany unilateral hearing differences. ▪ Congenital Cytomegalovirus (cCMV) – <ul style="list-style-type: none"> • Possible shared topic with Deafblind partners and • Impacts to Development, including communication • Intervention and available resources in Iowa. ▪ Collaboration between educational and clinical audiology practices, <ul style="list-style-type: none"> • Medical vs Educational approaches to interventions/services • How both types of resources impact students and families. • Tie in EI SLP, private vs educational models. ▪ Hospital and birthing facility screening and management updates: – <ul style="list-style-type: none"> • Ensuring that these providers remain updated on any changes statewide that may impact their services, <ul style="list-style-type: none"> ○ For example, services might be changing in the AEA and other tips of how to get kids re-screened outside of the AEA. ▪ Mental Health ramifications for families, siblings, children when hearing differences are diagnosed • Request for Ideas and topics to be sent to EHDI team for consideration
<p>12:45 – 1:15</p>	<p>Tele-Audiology Update (Tammy)</p> <ul style="list-style-type: none"> • Recap of July Advisory discussion regarding AEAs no longer available to conduct un-sedated diagnostic ABR assessment for babies in 1-3-6 process due to legislative and capacity changes. Additionally, there was discussion regarding exploring tele-audiology again, and how historically there were some challenges

with billing and connectivity. Some of the lessons learned with COVID-19 have made process of telehealth services more streamlined. From that discussion, Tonya was going to visit with the Director of CSHC to see if regional CSHC sites might be able to partner in offering tele-audiology services for diagnostic testing to help in meeting recommended best practice guidelines on diagnosis by 3 months of age:

- EHDI team update on where things are at:
 - Tammy met with Title V director. Offered to be a part of discussions. Felt it was a good fit.
 - Explored partnership for audiology piece with Wendell Johnson Speech and Hearing Center (WJSHC). They have audiologist there who is interested in conducting the assessment via telehealth, and they may be able to partner with EHDI and CSHC to provide telehealth diagnostic audiology services.
 - Tammy met with Utah EHDI program director on their partnerships with telehealth services, and got an idea of their successes with their program, protocol and discussed budgeting costs of what would be required to provide services
 - Discussed where we would need to have data analysis for provider needs to undertake this as a project
 - Talked to vendor about system needs and consumable costs
 - Tonya provided a list of questions from director to Tammy
 - Linda and Tammy pulled needed data for analysis
 - Tammy has had some family emergencies and work responsibilities come up recently that took time away from this project, but will be analyzing and sharing data with CHSC
 - Previously LTF had increased in previous years
 - Contacts to families, physicians and providers contacted to get children moved along in this process.
 - Gives us data about LTF and why that is happening – if telehealth will help improve LTF numbers.
 - Had been at 11.4% in 2019, but the last few years it started to go back up for several reasons, but in this past year, 2023, LTF has come down to 13.6%.
 - With AEAs not providing DX assessment, concerned that will impact numbers and family follow-up.
 - This may also be a way to avoid LTF, but we need to find a way to get the DX by 3 months improved. Current numbers do not show

	<p>improvement in the timeliness of diagnosis by 3 months.</p> <ul style="list-style-type: none"> ▪ Goal of EI by 6 months showed improvement, but still below recommended 80%. ▪ Looking at the number of children who need to be provided with services and what part of the state has the most need for telehealth. <ul style="list-style-type: none"> ○ Work with CHSC to see if this is feasible and can be piloted. ○ Tanisha requested that she is looped in on this conversation so the codes remain open for those provider types for reimbursement. <ul style="list-style-type: none"> ▪ Tanisha has recently helped EHDI with coding changes for Medicaid reimbursement related to the Hearing Aids & Audiological Services program ○ EHDI director and team continue to do epidemiologic study to find parts of the state where families travel the furthest, and where there would be location possibilities for telehealth partnership.
<p>1:15 - 1:45</p>	<p>EHDI Infrastructure Language Acquisition Needs Assessment National Partner Collaboration Letter (Linda/Tammy)</p> <ul style="list-style-type: none"> • HRSA grant has changed some of their guidance for both language acquisition and monitoring to 3 years of age: <ul style="list-style-type: none"> ○ HRSA is pushing language acquisition but not giving guidelines and very vague guidance of what is requested and what data will be used for ○ EHDI programs requested that federal partners work together before asking state programs work together, as EI programs nationally had not been given guidance on working with EHDI programs ○ OSEP/HRSA/CDC Joint Letter <ul style="list-style-type: none"> ▪ Dear Colleagues Letter linked on OSEP website ▪ August 5, 2024 ▪ This is the 1st time these agencies have come together with a joint agreement on partnership ▪ Federal Agencies encouraged all state programs to develop a coordinated system of care including: <ul style="list-style-type: none"> • Data sharing • Surveillance • Ensure early identification • Timely access to EI services • Fostering optimal outcomes ▪ Iowa has good relationship with EA, but many states do not and are not able to get data sharing agreements set up. ▪ When guidance first came out, it seemed like EHDI was being pushed into the educational

area for EI partnering. In Iowa, we had already communicated about what assessments are used.

- EHDl programs are required to provide data for children who are 3 years old, and the system will help provide some of that data by year 5
 - 1st year of Iowa EHDl project is focused on the needs assessment and provide data by year 5.
 - Not every state or within each state are the same assessments being administered, so trend and data comparisons may be difficult.
 - We were only able to identify ECO data as being consistently used throughout Early ACCESS in Iowa,
 - What language assessments are used has not been historically the focus from CDC.
 - When we submit our needs assessment, it may be clear that we need more guidance at a national level so that all agencies understand what is feasible for EHDl programs to provide and look at the ultimate goal of what the data will be used for.
 - EHDl programs want to ensure that children are moving through the system of care and meeting their outcomes in a timely manner.
 - EHDl programs want to honor all families as each family is different and their circumstances are unique.
 - EHDl is also working with non-part C providers to explore data in the private sector to look for trends and differences between private and Part C provider language acquisition interventions and protocols for working with DHH children.
 - Purpose should be to improve language development outcomes, but there are many variables to obtaining data.
 - Using Part-C non-part C providers
 - EHDl and EA explored variables that can be shared to report on required language outcomes and are in the process of updating their data sharing agreement.
- Other part of assessment is looking at Early Childhood screening and screening programs from birth through age 3
- With the AEAs possibly changing screening practices for infants and toddlers who are not referred through EA, EHDl will have to see how that will affect families and lost to follow-up.

- Early Head Start programs – will they still be able to use AEAs for hearing screening?
- Reporting to EHDI for Early Head Start screening is required by law.
- Looking for late onset or progressive hearing losses, hearing loss related to a risk factor identified at birth.
- The EHDI epidemiologist will be doing additional analysis on underserved populations and barriers to timely service provision
- Heather will gather input from families regarding services and supports that would be helpful in language development to include family perspective in the needs assessment narrative

The EHDI program hopes to bring this forward to work with Advisory to prioritize the plan to move forward with implementation of system changes.

1:45 – 2:45

Workgroup Activity/Discussion

- Family outreach beyond newly diagnosed children (e.g. Email package of resources for parents of toddlers and transition-aged children) and outreach to providers
 - Worked on providing more resources prior to aging out of services at age 3. Discussed what resources could be put together and ideas for what the packet should look like (physical/Virtual/folder).
 - Discussed how to disseminate to families
 - Package as a birthday gift packet prior to 3rd birthday
 - Fun resources from Hands and Voices
 - Student may be able to help for Capstone
- Physician outreach & physician packet newly diagnosed children
 - Exploring a packet for newly DX'd children and information and education/outreach for providers
 - Possibly using Iowa Early & Periodic Screening, Diagnosis, Testing (EPSDT) "Care for Kids" [EPSDT newsletter](#) to discuss best practices and provider resources. Tashina to reach out with contact for newsletter.
 - Suggestion to put together similar guide to the parent guide but might need to incorporate more technical terminology.
 - Fax instructions for referral for diagnostic ABR testing (vs other types of ENT/audiology appointments) including timelines for unsedated ABR and list of diagnostic centers – currently being done by EHDI
 - Follow-up
 - Utilize myths vs. Misconceptions document
 - Need to emphasize to physicians that the only providers who conduct diagnostic audiologic assessments are audiologists, not pediatricians or ENT physicians

- Education for physicians – need to get out the screening side of things and who can do the DX testing
 - Not AEA right now or ENT offices with non pediatric audiologists
- Also emphasis on unседated for timeliness
- Touch base on information sent out to physicians for dx needed
- Dr. Moriarty emphasized need for information and education for ARNPs and PA-Cs
- Also recommended including information about risk factors for delayed onset of hearing loss and who can monitor hearing delayed or progressive incidence of hearing loss in children
- Audiology (quarterly progress reports, protocol updates)
 - Audiologists had previously met via zoom to discuss possible metrics for quarterly reports
 - Linda shared that she and Tammy had gone through list to see what was feasible with the INSIS database to track, as well as what was backed in either best practices or Iowa law
 - It was discussed that quarterly reporting to diagnostic audiologic facilities was projected to occur in the upcoming year for these purposes:
 - To promote the goal of diagnosis of infants by 3 months of age as recommended by Health Resources and Services Agency Grant and the Center for Disease Control and Prevention
 - To provide consistent and equitable practice amongst providers of diagnostic assessment to Iowa's children.
 - The subcommittee agreed upon the following metrics and discussed timelines to be surveilled and reported to facilities providing diagnostic testing on infants within the initial 1-3-6 hearing healthcare journey:
 1. Diagnostic testing by 3 months of age indicating type of hearing difference as based on JCIH 2019 recommended standards
 2. Referral to EI upon diagnosis of hearing differences as based on JCIH 2019 recommended standards.
 3. Reporting of diagnostic testing to child's EHDI record within 6 business days as mandated by Iowa Law
 4. Repetition of outpatient screening following diagnostic assessment referral without medical rationale as based on JCIH 2019 recommendations
 5. Number of Not Yet Determined Outcomes prior to Diagnosis Confirmation Outcome or referral to EI as based on JCIH 2019

	<p>recommendations and evidenced by Jassen et al and Hearing (Ear Hear. 2010 Oct;31(5):722-4. doi:10.1097/AUD.0b013e3181ddf5c0. PMID: 20473179.</p> <p>6. Number of Days between First Diagnostic ABR Session and Confirmation of ABR to exceed timeline greater than 3 months of age (JCIH 2019 recommendations)</p> <ul style="list-style-type: none">○ Diagnostic providers and facility administrators who are out of compliance with best practice standards will be given feedback in order to initiate plans for remediation or protocol changes, if feasible.
2:45 – 3:00	<p>Closing, Next Meeting Topics Continue using the time for work groups on areas we are working on in our program and needs for our state.</p>

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

****ACHIEVE Family Portal Slidedeck Below:**



ACHIEVE
I o w a I D E A



ACHIEVE Family Portal Preview



Introductions & Agenda

1. **Who** can access the ACHIEVE Family Portal?
2. **What** does the ACHIEVE Family Portal provide?
3. **Where** is the ACHIEVE Family Portal located?
4. **Why** might families/learners use the ACHIEVE Family Portal?
5. **How** can families/learners get more information about the ACHIEVE Family Portal?



Who can access the ACHIEVE Family Portal?

Eligible Account Holders

IDEA Parents

- Parent (Biological or Adoptive)
- Relative acting as Parent (IDEA)
- Legal Guardian of Minor
- Legal Guardian of Protected Person
- Court Designee
- Power of Attorney
- Surrogate

Special Education Learners

- **Prior to reaching Age of Majority/Date of Rights Transfer:** May be invited with view-only access by IDEA Parent
- **Upon Reaching Age of Majority/Date of Rights Transfer:** Automatically invited if valid email address is on file

Individuals who cannot be invited to the ACHIEVE Family Portal

- Parent (Other)
- Foster Parent*
- Relative
- Friend

**Foster parents may be eligible if another criterion as an IDEA Parent is met (e.g., Relative acting as Parent (IDEA); Surrogate)*



What does the ACHIEVE Family Portal provide?



ACHIEVE Family Portal

What it IS:

- **Real-time access to learner records**
including and not limited to:
 - Finalized IFSP/IEP plans
 - Progress monitoring data
 - Electronic consent forms
- **Repository of view-only records to be accessed, downloaded or printed**
- **Calendar with information about upcoming dates and meetings**

What it IS NOT:

- **Requirement for Account Access**
 - IDEA Parents choose whether to create account
 - Access to records and information must still be provided outside of the ACHIEVE Family Portal
- **Replacement for person-to-person collaboration**
 - IFSP/IEP meetings are still required
- **Ability to request or edit IFSPs/IEPs**
 - Users cannot update existing documents but can download/print and bring to meetings



**Where is the ACHIEVE
Family Portal located?**

Family Portal



Sign In

Email

Password

[Forgot password?](#)

The ACHIEVE Family Portal:

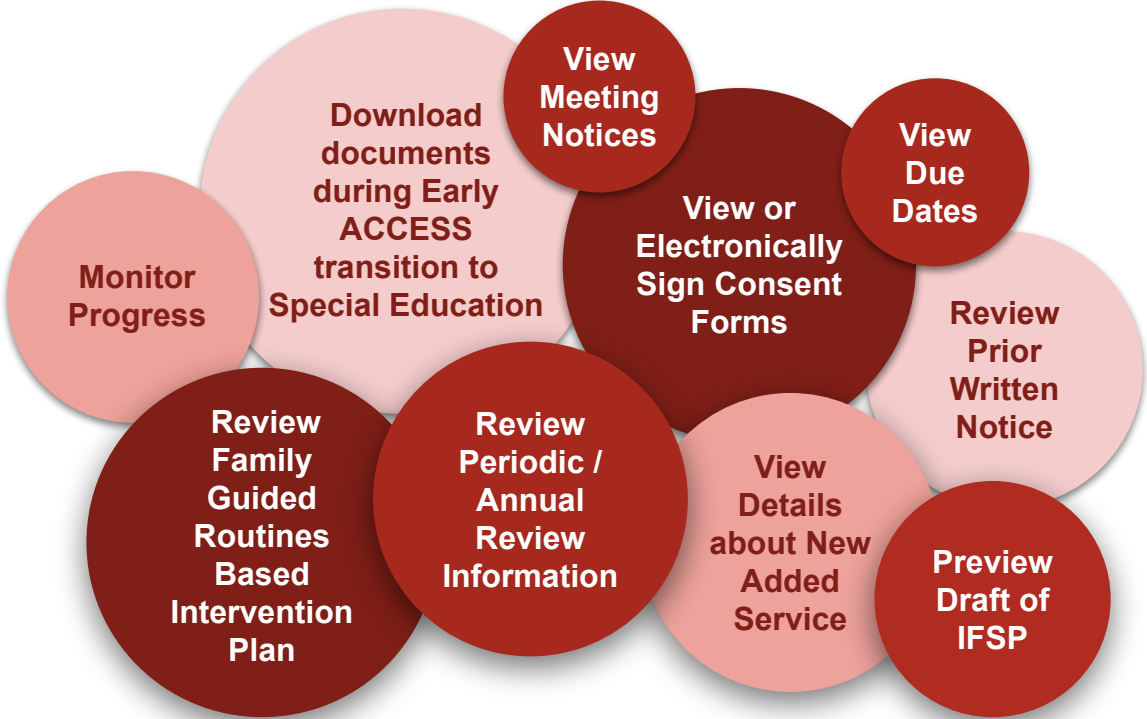
- **Supports** families and children transition seamlessly as they age from Early ACCESS services through Special Education.
- **Empowers** families, learners, and teams to collaborate in a shared system and allows for more informed decisions on what works best for each individual learner.
- **Engages** families and learners to view, print, and sign documents electronically, and view real-time progress on outcomes and goals so all learners can “achieve” and succeed.



Why should families use the ACHIEVE Family Portal?

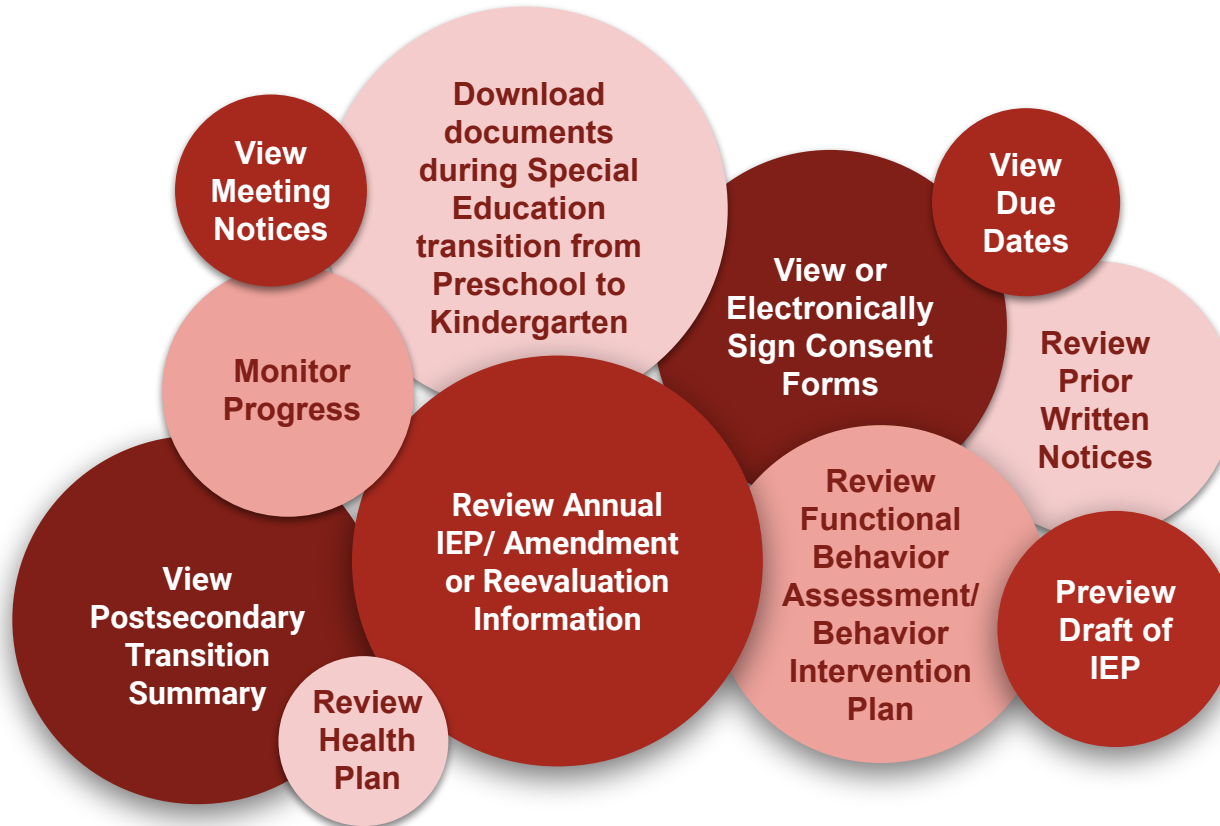


Early ACCESS Scenarios





Special Education Scenarios





**How can families/
learners get more
information about the
ACHIEVE Family Portal?**



Training Videos

ACHIEVE Family Portal Overview

- What is the ACHIEVE Family Portal?
 - What it does
 - What it doesn't do
- Family/Learner Benefits
- How/When Accounts can be Created
- Access Types
- Multiple Learners

Early ACCESS: IFSP (Birth-3)

- Overview of Early ACCESS screens
- Examples of when and why families access ACHIEVE Family Portal and how to find corresponding information
- Early ACCESS Exit / Transition

Special Education: IEP (3-21)

- Overview of Special Education screens
- Examples of when and why families access ACHIEVE Family Portal and how to find corresponding information
- Special Education Exit / Postsecondary Transition

Impacts to Early ACCESS/Special Education Teams

- Overview of ACHIEVE changes to support rollout of ACHIEVE Family Portal
- Details on differences between case owner view vs. ACHIEVE Family Portal view
- Validation Process



ACHIEVE Family Portal Launch Toolkit

**ACHIEVE Family
Portal Getting
Started Guide**

**Frequently
Asked
Questions**

**ACHIEVE
Webpage**

**Training
Videos**

**Family Portal
User Guide**