

### **PROVIDER EARLY ACCESS REFERRAL TIPS**

Early Intervention Part C/Early ACCESS services are determined upon the informed and educated consent or decline of the parents. Informed consent is defined by the Oxford Dictionary as: *permission granted in the knowledge of the possible consequences, typically that which is given by a patient to a doctor for treatment with full knowledge of the possible risks and benefits.* 

\*\*\*PLEASE NOTE: Regardless of whether or not a family chooses to be referred for Early ACCESS/Early Intervention Part C services, families of children diagnosed with hearing loss are entitled to Family Support through the Iowa Early Hearing Detection and Intervention (EHDI) office. For more information about Iowa EHDI Family Support Services, please visit the EHDI Family Support Website link.

Early ACCESS Referral Step-by-Step Process:

There is an online statewide system for submitting a referral to Early ACCESS, Iowa's Early Intervention Part C service, which includes an easy-to-use online referral form. To make a referral:

Patient	Outcomes:								
	Description			Status			Appointment		
Birth Sc									
Outpatie		Unilate	ral Referra	al .		~ (			
Risk Mo	Risk Monitoring		Not Required						
Audiolog		Requir	ed - Pendir	าต		~		oo 📔	edit
ENT			quired						
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	Screen Type 🗸	Facility							
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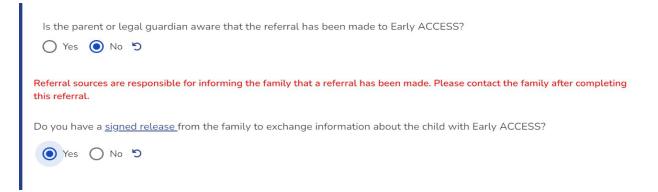
1.) Go to the URL: <u>https://achieve.iowa.gov/early-access-referral</u> or click on the Make an Early ACCESS referral link in the INSIS system:

2.) Fill in the information on the child, parent, referral source, referral reason and documentation by tabbing across the top:

ild Info	Parent Info		Referral Source Info	Re	eason for Referral	Document	tation
Child Informati	on						
irst Name*	М	iddle Name	Last Name*		DOB (MM/DD/YYYY)	•	Ē
ield is required			Field is required		Field is required		
Gender	-				er Needed*		
○ Female ○ M		Primary Language Spoken in Home*		- O Yes	O No 5		
5	F R	aid is required		Field is requ	ired		
Residential Info	ormation						
Street Address* Z		Zip Cod	Zip Code*		×	State*	-
Field is required Field		Field is rec	quired	Field is require	Field is required		

3.) When you reach the Referral Source Info tab, there will be a yes/no question asking if the parent is aware that a referral is being made. Answering this question helps the Early ACCESS service coordinator to know how to address the parent when calling. (see image below)

4.) There will be a second question asking if there is a signed release to **exchange information** regarding the child. Please consider having the family sign an exchange of information, instead of just a release of information when they are at your office so that there can be two-way communication. That way, you can refer and relay information about the child to the Early ACCESS service coordinator, **AND** you may receive information from Early ACCESS team members about the child you have referred.



information, so that there can be an ease of sharing information. Again, this helps support the child by allowing providers to communicate about their needs.

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Child Info	Parent Info	Referral Source Info	Reason for Referral	Documentation
Supportin	ng Documentatio	on		
Documentation	n uploads are optional. Ex	amples of documentation that may	be helpful include the following:	
• Consent	to Release and Exchange	Information		
Documen	tation Uploads			
Uptoad				
Please Note: Ea	arly ACCESS cannot shar	e information until a signed permis	sion from the family is received.	
			Previous	Complete Referral

\*\* It is important to get a signed exchange, even if a family declines services. If a family declines, we can then get feedback from Early ACCESS that they have declined at this time, for whatever reason. However, it also allows us the opportunity to remind families at a later date of Early ACCESS services and supports that their child is *automatically entitled to receive at no cost* to help with communication and family support from birth to 3.

Please note that if you prefer to speak to someone, referrals can continue to be made by contacting the Iowa Family Support Network at 1-888-IAKIDS1 (1-888-425-4371).

\*\*\* Indicate in EHDI Database if referral has been made or suggested **REGARDLESS** of whether or not the parents choose a referral or decline a referral. You can choosed "decline" in the case management notes as an option.

### EA REFERRAL SCENARIOS:

Below are a few scenarios that could occur in an audiologist's office following a diagnostic evaluation of a baby. This is a time when audiologists are trying to give parents information, but not overwhelm parents. We have also provided some parent feedback so that providers can understand what a parent might be thinking at the time of a referral. These situations are intended to allow parents and providers to understand where the other is coming from, and to allow understanding of each other's perspective.

### For Providers:

# Family Agrees to Early ACCESS/Early Intervention Part C referral following Diagnosis

**Scenario 1**: You are seeing a 2 month old child who has failed their newborn hearing screening, and subsequent outpatient hearing screening. The parent informs you that

they are very scared about the possibility of their child having a hearing loss. They also report that their child has had a cold and maybe the hearing concerns are due to that, as one of their older children has a history of ear infections. Diagnostic testing at your facility indicates a moderately severe hearing loss, which is potentially mixed, but definitely has a sensorineural component. You are most likely going to see this family for future appointments to ensure the degree of sensorineural hearing loss with additional diagnostic testing, schedule a hearing aid evaluation (HAE), and refer out for ENT consultation and medical management.

**Family Perspective** 

• As a parent, this is likely the first time I have ever experienced anyone with a hearing loss, and there is no family history. I have no background knowledge of what this means for my child, or what resources are available to us. A hearing loss was not at all expected, and I am grieving what that will mean for my child and how it affects them. I still don't completely understand how much hearing loss my child has or why. Our audiologist informed us at our appointment about some resources available for families as well as Early ACCESS and how they can benefit our child. I was not sure what that meant, but they explained the process, how it works, and what they do. We want to utilize any information and resources we can find to help our child and have agreed to a referral with Early ACCESS and are excited to start working with them. I need to know that my provider is available for me after appointments to ask any questions I may have after I take time to process the information and resources offered.

**Professional Perspective** 

- As a professional, you want to inform the family of the diagnosis, and educate them on the resources available. The family may want to defer this conversation to their next appointment, but that is the family's decision, and not the provider's. All parents will react to this information differently, so it is important to allow the family to lead the conversation on additional resources, if possible. It is not the provider's responsibility to decide for the parent what they can and cannot handle at this time.
- Even if you are planning on seeing the parent back for a hearing aid evaluation following additional testing and medical management, the referral for Early ACCESS can occur without an HAE or ENT medical clearance for a hearing aid. Parents may decide not to pursue hearing aids, but are still entitled to Early ACCESS support.
- Despite the degree of sensorineural component, the fact that this child has a permanent hearing loss (either SNHL. mixed or permanent conductive) entitles them to Early ACCESS services.

Permanent hearing loss is an automatically qualifying condition.

**Next Steps** (based on JCIH Best Practice Guidelines and Iowa Family Support Process):

- 1) Refer for medical management
- 2) Sx additional hearing testing, with appointment having adequate time to allow for all appropriate communication options to be discussed with parents
- 3) Discuss Early ACCESS/Early Intervention referral with parents
- 4) Signed Exchange of Information to upload with EA referral
- 5) Document Referral process in the child's EHDI record in the INSIS Database

## Family Declines Early ACCESS/Early Intervention Part C referral following initial diagnosis

**Scenario 2:** You are seeing a 5-month-old boy who was referred from an ENT office. This child has had multiple upper respiratory and ear infections since birth. Your audiologic evaluation indicates a severe hearing loss, and bone conducted ABR testing indicates a moderate degree of sensorineural hearing loss probable. Tympanometric testing indicates normal compliance but significant negative pressure, indicating a possible conductive component to the hearing loss. You discuss the results with this family, and they report to you that their doctor has told them that the hearing loss is likely due to ear infections, and once they are cleared, their child will hear "just fine." This family is scheduled for PE tube testing in 2 weeks with the referring ENT provider.

Family Perspective:

We have no family history of hearing loss, and our baby has been sick a lot with multiple ear infections. I don't think there will be a problem with his hearing if we can clear up the infections. At our audiology appointment, they discussed with us the possibility of permanent hearing loss and wanted to refer us to Early ACCESS. At this point, I want to have follow up testing to see what his hearing actually is before we commit to anything. If things are still looking like a permanent loss, we would appreciate a more in depth conversation of the resources available and what the process is for things like Early ACCESS. I need to know that my provider is available for me after appointments to ask any questions I may have after I take time to process the information and resources offered.

Professional Perspective:

• As audiologists, we are charged with the importance, education and treatment of receptive language ability via hearing. An ENT

provider is charged with the medical health of the ear, our job is ensuring "hearing" healthcare and offering communication tools for receptive language. When discussing Early ACCESS/Early Intervention with a family who is concerned about ear health, do not be afraid to educate and empower families about hearing and receptive language, and its impacts on a child's communication, behavior, and social development skills. An Early ACCESS referral is a gateway to involving families in the development of these skills with their child. Educating parents on the aspects of communication that may be impacted by a diagnosis may help them to understand the importance of an Early ACCESS referral, instead of focusing only on hearing aids or cochlear implants, which are tools to their child's language development.

• If the parent wishes to wait for this conversation until after an ENT appointment, document the conversation and make sure to discuss after the post-operative hearing evaluation.

### Provider Steps:

- 1) Report results to referring ENT, including that an Early ACCESS referral was made and declined by parents
- 2) Ensure that the child has follow-up hearing testing scheduled at your facility; do not rely on the ENT provider to refer the child back to your facility. If a child's ear is healthy, the ENT has provided medical management; however, we are charged with hearing healthcare, so the onus of ensuring audiological follow-up lies on audiologists.
- 3) Ensure that time for additional audiologic testing includes time to discuss any communication options and an Early ACCESS referral and support. Document the Early ACCESS discussion in the child's EHDI record in the INSIS database.

# Family Continues to Decline Early ACCESS/Early Intervention referral following Amplification or Communication Interventions:

**Scenario 2 continued:** Continuing the above scenario, the family comes back to your office following PE tube placement, as their child still does not pass hearing screening at the ENT office. You are able to get diagnostic testing that does indicate a moderate bilateral hearing loss. The family decides they would like to consider hearing aids. Fortunately, you are able to make earmold impressions and RECD measures while the child is still sleeping. An appointment is tentatively scheduled for 2-3 weeks for the family to return for hearing aids. You again **mention** Early ACCESS services, but the family does not wish to pursue an EA referral at this time.

Family Perspective:

• After follow up testing we were told there is still a permanent hearing loss. This news to us is very hard to hear as we were sure his hearing would be fine if we could clear up the infections. We decided to move forward with hearing aids. There is a lot of information being given to us and it seems like too much to process all at once. We are feeling very overwhelmed and just want to focus on our child. He is also still very young and I'm not sure if we would need the services they are talking about. After we have had some time to process all of this information and get used to the new technology, a more in-depth conversation about these services would be easier for us to process and think about. I need to know that my provider is available for me after appointments to ask any questions I may have after I take time to process the information and resources offered.

Professional Perspective:

- Be aware that your "buy-in" to the importance of Early ACCESS is going to be noticed, even subconsciously, by parents. If you mention it as a "yes, this is something you could do" but don't stress the importance of it, those cues will be picked up by the family. Early ACCESS supports for children with hearing loss in a variety of ways, even some that might help you (consider that the audiologist or teacher of the deaf going to their house can help in ensuring the hearing aids are worn and in the child's ears properly). Additionally, this allows a family to begin working with the educational team that will be monitoring their language development, and that can help you to know how the child is functioning with their hearing aids from another professional viewpoint. If the parents are adamant about not wanting an Early ACCESS referral, periodically discuss EA referral as part of the resources you use to educate and empower parents.
- Parents may tell you concerns at a future appointment that you can help educate them about Early ACCESS:
  - It is free
  - It can be done in their home, there are no travel expenses
  - It is a tool for family engagement
  - Even if a family plans to home-school, they are entitled to receive services
- Continue to take cues from the parent about services. If a parent tells you about a concern with how the child eats, sleeps, talks, walks or behaves, these can all be areas where a family can receive support. A parent of a child with hearing loss can have an EA provider addressing an eating concern, even if they do not utilize them for communication. A parent can pick and

choose the services that are best for their family.

#### Provider Steps:

- 1) Continue with hearing aid follow-up as appropriate
- 2) Continue to discuss EA referral at appointments, especially if the parent voices concerns about language development, behavioral concerns or lack of socialization. It is extremely important to discuss if the family indicates that the child has stopped or has reduced their expressive language, and you are finding that they are wearing their amplification appropriately.
- 3) Document conversations about EA as a general or hearing case note, in the summary of the audiologic assessment, or in the case management section of the child's EHDI record in the INSIS database.
- 4) Take your lead from the parent. If they want to wait to discuss EA at a later time, make sure that you do bring it up at subsequent appointments.

### Follow-up by EHDI Family Support

Regardless of whether or not the family would like to be referred for Early ACCESS services, they are entitled to Family Support in whichever manner they choose. In Iowa, a family may wish to pursue talking with another family to see what to expect, and can be matched with a Family Partner. Additionally, if the family would like to have more tools for sign language, talking to a person with hearing loss, or how a person with hearing loss or deafness feels, the family can be matched with a Deaf Partner. Other services, such as a family book club, facebook page, family events, and more can be accessed by professionals and families through the <u>EHDI family support link</u>. Again, family support is offered through the EHDI program as an independent service of Early ACCESS support.

### **Resources:**

### lowa EHDI Website:

Iowa EHDI 1-3-6 Iowa EHDI Best Practices Page JCIH 2019 Position Statement (pages 1-4) EHDI Family Support Page Hearing Loss Checklist Hearing Follow-up Flowchart What is Iowa Early ACCESS: Early ACCESS -- Iowa Code DOE Administrative Rules Iowa Family Support Network IDEA Part C Part C Regulations 8 Reasons Why to Say Yes to El <u>Free Early ACCESS Materials</u> <u>5 Reasons to Say YES to Assessments in Early Intervention</u>

Best Practice for EA follow-up by Joint Committee on Infant

Hearing 2019 Position Statement (pages 23-27)

ASHA Resources

What is Early InterventionEHDI and Intervention-Pediatric Audiology Links to Services (EHDI-PALS)State Early Intervention Coordinators - Early Childhood Technical AssistanceCenter Hearing to LearnLearn the Signs. Act Early. - CDCASHA Language Equality and Acquisition for Deaf Kids (LEAD-K)

Page Language Equality and Acquisition for Deaf Kids (LEAD-K)

Resources

LEAD-K Webpage lowa House File 604 lowa School for the Deaf LEAD-K Page ASHA Language Equality and Acquisition for Deaf Kids (LEAD-K) Page lowa Deafblind Project Hands & Voices ASK Resource Center AG Bell