IOWA | Health and Human Services

EARLY ACCESS REFERRAL TIPS FOR PARENTS

Early Intervention/Early ACCESS (EA) services are determined upon the informed and educated consent or decline of 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.***

Parents and guardians as well as providers are able to make Early Intervention/Early ACCESS referral by going to this link and submitting your information. Please make sure you sign an exchange of information so the Early ACCESS Service Coordinator can consult with your Audiologist.

> ** It is important to sign an exchange, even if you decide to decline services at this time. *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).*

Regardless of whether or not your family would like to be referred for Early ACCESS services, you are entitled to Family Support in whichever manner you choose. For more information about Iowa EHDI Family Support Services, please visit the EHDI Family Support Website.

Early ACCESS 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 information to parents, but not overwhelm parents. We have also provided some provider feedback so that parents can understand what a provider might be thinking during these conversations with families. These situations are intended to allow understanding of each other's perspective.

> **Scenario 1**: *You have a new baby that you were just informed has a diagnosis of moderate-severe hearing loss. You feel very worried, wondering about what this means for your child and your family. Are there any resources available to help? You want all of the information you can find and to connect with other people who have been through*

the same thing. You have not had any experiences with people with hearing loss before and you do not know where to turn for help.

Family Perspective

- I really want my provider to have a conversation with me about any resources that are available to us. I would like to have the conversation as well as written information to refer to later so I can look it over and have time to process. I don't know what this diagnosis means for my child or what their future looks like. I need more information in order to make decisions.
- I want to know if there are services that can help my child with communication and any support for us to meet other families that have children with hearing loss or adults with hearing loss.
- 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:

- I really want to help this family get the support they need. I can see this is a very hard situation for them, and I am concerned about pushing too hard with resources. I want to make sure that they know there are more resources available, but I don't want the family to think I am pushy.
- I can provide education regarding hearing differences and the services offered by my office, but can refer to Early ACCESS so that the family is able to be educated on many more resources and language approaches than I have available here.
- I am an expert on hearing differences and hearing aids, but don't know as much about American Sign Language (ASL) or LEAD-K. I know these might be important for the family to understand, but I don't have as much experience, so I can provide the family with other resources and connections to learn more.
- Because they have no family history and use spoken language, talking with the family about hearing aids lets them know about this option; however, I want the family to be informed of other options available to them. (example: different communication modes such as ASL or other communication modes.)

- I am aware that this family may move or decide against hearing aids prior to having them fit, so I want to make sure this family has the resources they need if they never return to my office.
- I want to make sure that I have this family sign a release of information, so that I can communicate with the educational audiologist on the Early ACCESS team, and make the team aware of any changes or concerns the parents discuss in my office regarding services.

Parent Steps

- Have a discussion with your provider about what services are available.
- Make sure you are referred to Early Intervention/Early ACCESS before you leave the appointment so you can get started with services.
- Take the information for all resources home with you so you can refer back to it as needed.
- Decisions need to be made for your child as far as amplification options if chosen, as well as communication mode/modes. It’s important to know that just because you make one decision now doesn’t mean you can’t change that decision in the future depending on the needs of your child.
- If you have questions regarding communication modes, you can ask those at any time. If the provider you are working with does not know how to answer your questions, you can ask for additional resources or contact your EHDI Family Support Coordinator.
- Discuss the options available with your provider and get information to take home to make an informed decision.

Scenario 2: *My 5-month-old son has been sick a lot since he was born with what seems like constant ear infections. We have been seeing an ENT to try to help him, but they also sent us to an audiologist for a hearing test. The audiologist told us our son has a diagnosis of permanent hearing loss, but our doctor and I feel like his hearing may be fine after the infection clears up. They talked to us about Early ACCESS and resources available for families, but I don't feel like we need those at this time, and I want to come back another time for follow up testing to see what his hearing is like then.*

Family Perspective

- I would like my provider to discuss my child's diagnosis and what that means for them. I want to have a conversation with my provider about available services and resources but I am very overwhelmed.
- I would like my provider to give me all of the information about services and resources now both via a discussion and papers to bring home so I have time to process the information and look at it later.
- I'm still not sure I agree with the diagnosis of permanent hearing loss and would like a second opinion before I agree to anything. If the follow up testing still shows a diagnosis of permanent loss, I would like to have a discussion again about what our options are as far as services and support for my child.

Professional Perspective

- It is frustrating for me that a medical provider is not allowing the parent to have all the information about hearing and communication, because their focus is on the health of the ear, not if the child can hear. I really want to talk to the parent about the seriousness of the lack of language development that can happen with a diagnosis of permanent hearing loss or even temporary changes in hearing levels, but I am afraid they will not listen to me because they feel that their doctor has told them everything will be "fine" without having the testing to back up that statement.
- I can provide that parent with Early ACCESS information and refer them on to Early ACCESS. The Early ACCESS

provider can give the family information about communication and learning, even if the family is not able to accept that their child has a permanent hearing concern.

- I can refer this parent to EHDI family support services to connect them to other families. That communication could help the family accept and consider more communication tools for their child that I could discuss with them.
- One important thing I can do is ensure I have reported the results to this child's medical provider. I have very clearly stated the child's hearing concerns, possible communication tools to offer this family and the ramifications for communication if this child's diagnosis of hearing loss is not addressed.
- I have entered the results into the EHDI database, including the conversation with parents so when EHDI follow-up support and Family support contact this family and their provider, we can work together from our perspective lenses to try to empower this family to understand the difference between a medical ear concern and a hearing concern.

Parent Steps

- Have a conversation with your provider about available services and resources including Early Intervention/Early ACCESS.
- Make sure you have an appointment scheduled with the audiologist for a hearing retest.Take home information for resources so you can look through it in the meantime while you wait for your next appointment.
- Make sure you are monitoring your child's language growth and developing communication skills.
- If you have concerns about your child's development or hearing before your next appointment, do not hesitate to contact your provider sooner.

Scenario 3: *Our son received tubes and we came back for another hearing test with the audiologist. They inform us he still has hearing loss and it would be best to move forward with amplification options. They also talked to us about Early ACCESS Services and resources. This is a lot of information to take in all at once.*

- I am very overwhelmed knowing that our son has permanent hearing loss. I need our provider to explain it to me in words I understand.
- I also need to have another conversation about available services and resources now that we know the hearing loss will not go away when infections are cleared up. I would also appreciate everything given to me on paper to take home and review as well as this is a very emotional time and I want to be sure I understand everything.
- 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

- I have many resources to give to this family, but I don't want to overwhelm them.
    - I will talk with them about communication resources, including amplification and non-amplification communication options. I will leave extra time in case there are questions.
    - I will discuss Early ACCESS with them, regardless of whether or not they decide to choose amplification.
    - I will discuss EHDI Family Support so they have another resource to talk through resources, including parent support.
    - I really want to establish a trusting relationship with this family, because the diagnosis of their child's hearing loss is permanent and I may be involved with them for a long time. I want them to know that I really care about their child's development. I will take this conversation home with me and wrestle with whether I handled this correctly.

Parent Steps

- Have a discussion with your provider about Early Intervention/ Early ACCESS and resources available.
- Make sure your provider refers you to Early Intervention/Early ACCESS before you leave your appointment. If you want time to decide, make sure you let them know you want to discuss Early ACCESS again after you have had time to look through the information.
- Take home any resources given to you so you can refer back to it as necessary.

- Make sure you are monitoring your child’s language growth and developing communication skills.
- Decisions need to be made regarding communication mode/modes. It’s important to know just because you make one decision now doesn’t mean you can’t change that decision in the future, depending on the needs of your child.
- You may need time to consider amplification, but language decisions should be made quickly.
- If you have questions regarding communication modes, you can ask those at any time. If the provider you are working with does not know how to answer your questions, you can ask for additional resources or contact your EHDI Family Support Coordinator.
- Discuss the options available with your provider and get information to take home to make an informed decision.

Follow-up by EHDI Family Support

Regardless of whether or not your family would like to be referred for Early ACCESS services, you are entitled to Family Support. In Iowa, a family may wish to talk with another family to see what to expect, and can be matched with a Family Partner. A family partner is another family who has a child with a diagnosed hearing loss. If the family would like support for learning ASL, would like to talk to a person with a hearing difference, or have a better understanding of life as a person who is Deaf or Hard-of-Hearing, the family can be matched with a Deaf/Hard-of-Hearing Partner. Other services, such as a family book club, Facebook page, family events, and more can be accessed by professionals and families through the EHDI Family Support link.

Resources:

Iowa EHDI Website:

EHDI Family Support Page
Iowa EHDI 1-3-6

  - Iowa EHDI Best Practices Page
  - JCIH 2019 Position Statement (pages 1-4)

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 EI
  - 5 Reasons to Say YES to Assessments in Early Intervention
  - Free Early ACCESS Materials

Best Practice for EA follow-up by Joint Committee on Infant
Hearing 2019 Position Statement (pages 23-27)

ASHA Resources

  - What is Early Intervention
  - EHDI and Intervention-Pediatric Audiology Links to Services (EHDI-PALS)
  - State Early Intervention Coordinators - Early Childhood Technical Assistance
  - Center Hearing to Learn
  - Learn the Signs. Act Early. - CDC
  - ASHA Language Equality and Acquisition for Deaf Kids (LEAD-K) Page

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

  - LEAD-K Webpage
  - Iowa House File 604
  - Iowa School for the Deaf LEAD-K Page
  - ASHA Language Equality and Acquisition for Deaf Kids (LEAD-K) Page

Additional Family Support Organizations

  - Iowa Deafblind Project
  - Hands & Voices
  - ASK Resource
  - Center AG Bell