



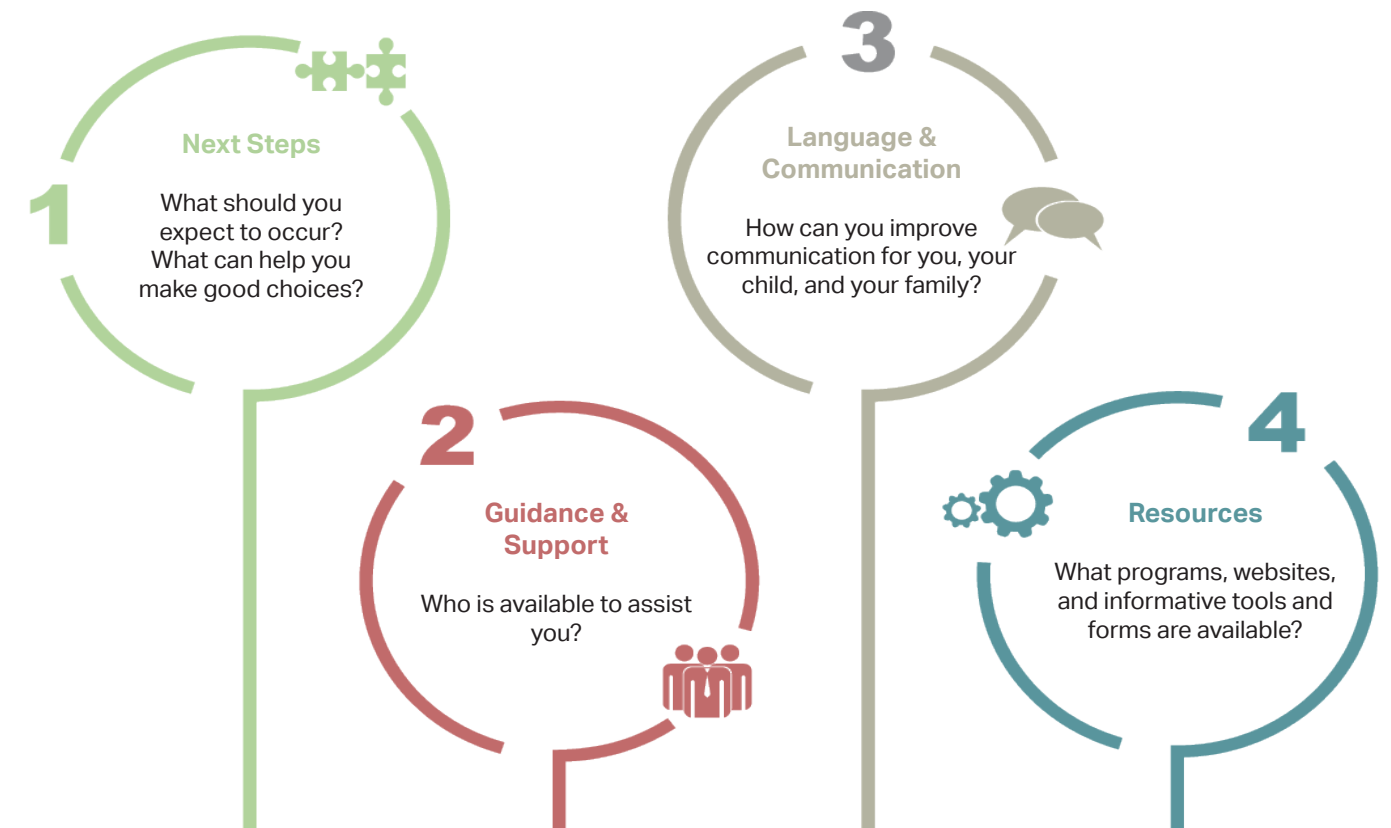
EHDI Program Parent Guide

Dear Parents and Guardians,

We are writing to you as a parent or guardian of a child with a newly diagnosed hearing loss. Our hope is that this guide provides you with next steps and gives you hope and encouragement.

Many families say that knowing how to get started is what helped them the most. This Parent Guide is designed to help you through this important and overwhelming time. You may go through many different emotions. All of those feelings are okay. They will be different for each family member. Wherever you are in this process, please remember that your child is a wonderful gift. There is a bright future ahead for him or her.

In this guide, you will find information about:



Early Hearing Detection and Intervention (EHDI) Program
Lucas State Office Building
321 East 12th Street
Des Moines, Iowa 50319

When deciding the next steps for your child, it is important to act quickly. You want your child to learn language as soon as possible. Remember, decisions you make today are not set in stone. Your next steps will change as your child changes.

Finally, please take the time to review the information in this guide. We ask that you complete a survey (www.surveymonkey.com/r/ParentswithEHDI) to let us know if this guide contains the resources your family needs. Your responses will be used to improve the guide and help Iowa families just like yours.

Sincerely,

Iowa's Hearing Detection and Intervention (EHDI) Program
<http://www.idph.iowa.gov/ehdi>
(800) 383-3826



Planning Your Journey

Identification of Hearing Loss and Understanding the Diagnosis

The next steps will depend on your situation and your child's needs. Let's begin with helpful, accurate information. Here are five important steps you can take:

Receive support while you learn.

Connect with early intervention and family support groups. You can learn more and receive support and feedback from others who have good information.

Take care of your needs.

Like your child, your needs will change. Be aware of your needs. Seek out helpful people and services. Remember that your child will learn how to take care of themselves from you.

Choose what is best for your family.

Continue learning so you can make the best decisions as your needs change. Learn about common steps other families take. Consider whether these will work for your family. Your decisions may change as you receive new information. Parenting choices are best made in small steps.

Be an active player in your child's journey.

Be your child's best supporter. You are your child's first and most important teacher. Because of this, it is important to stay informed and to understand your child's diagnosis. Create a care notebook to outline and track your child's needs and plan of care. Find more information at www.idph.iowa.gov/ehdi.

Create a team that will support your family's needs.

Carefully choose who will be on your team. The team's support and information will help you make decisions. Know who is on your team and be an active member yourself.

Every year around 24,000 children are born in the U.S. with some degree of hearing loss.

Of the over 39,000 babies born in Iowa each year, approximately 80 will be diagnosed with a hearing loss shortly after birth.

Another 2 to 3 percent will be diagnosed with late onset (after birth/before kindergarten) hearing loss.

Learn More!

There is so much to learn! Look for well-researched information about the types of hearing loss, types of hearing devices, communication options, language resources, and other topics. It is important to keep learning as your child learns. Below are a few resources for families in Iowa.

Parent support groups can be a great source of support. These groups offer emotional support and unbiased information. The members have common interests. They share their knowledge and experience with each other. To learn more about parent support groups, call (800) 383-3826 or visit www.idph.iowa.gov/ehdi/families.

Family stories are an important resource. By receiving and sharing stories, families learn from each other's journeys and feel less alone. Stories can offer support, information, and advocacy to you and to other families. If you are interested in sharing your story, please complete this survey: www.surveymonkey.com/r/ParentswithEhdi.



Hearing loss is a physical condition that allows you to receive Early ACCESS services. A child can receive Early ACCESS any time from birth until 3 years old. Services focus on talking, moving, seeing, listening, thinking, and communicating. Many of the services help with child development and school readiness. For more information or to request services, contact Early ACCESS at (888) 425-4371 or visit www.iafamilysupportnetwork.org/early-access-iowa.

The EHDI website contains information about resources and services for children with hearing loss. It also contains information about recommendations and best practices. Learn more about childhood hearing loss, hearing testing, and important questions you should ask at www.idph.iowa.gov/ehdi/families.

Your Communication Toolbox

You and your child have communication options. Choose what works best for your family.

What is a communication tool box?

As in a common toolbox, communication strategies are tools that help you communicate with your child. You can choose the contents of your family's communication toolbox. This toolbox should encourage your child's learning of language and communication.

1

Strategies for communication and learning language should be started as soon as possible after the hearing loss diagnosis.

If you are unsure about what is available, talk to your support team. Remember, timely decisions will help your child's development.

2

Remember that the tools in your toolbox may change.

What works for your child today may not work tomorrow. Talk with your support team. Decide which strategies are working. Think about how your child's development and lifestyle are changing when making changes to your communication strategies.

3

Whatever language strategies you use, know that you will need to learn alongside your child.

You may learn a signing system with your child. You will also create new pictures to exchange with your child as their vocabulary increases. Remember, you are your child's first and most important teacher.

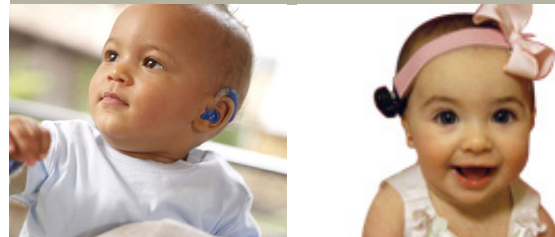
4

Choose any tool or tools you need.

Any number of communication strategies may be combined. No one strategy needs to stand alone.

Amplification Supports

include hearing aids, BAHA and cochlear implants.



Non-amplification Supports

include manual communication, signed language and cued speech



Your choices affect your child

Understand the choices in your community and what will fit with your family. Choices may change as your child's needs change or if a tool isn't effective. Be aware of your choices and the supports available. Make informed decisions as quickly as you can to meet deadlines and your child's changing needs.

Next Steps

Understand who is on your support team and what they do. They can help you make decisions about your child's future. See below for brief descriptions of professionals and family supporters who might be on your team.



Audiologists will provide you with information about your child's hearing loss and communication options. Your audiologist may also assist in accessing funding to support your communication options. This provider will be a key part of your child's ongoing care. Audiologists might work for an Area Education Agency, a private company, or a clinic/hospital.



Primary care providers (PCP) is your child's main doctor. Your provider will make referrals to others — such as speech and language pathology, genetics, cardiology, and nephrology. This helps rule out other factors that may affect your child's development and hearing loss. Your provider will monitor your child's hearing status and development in scheduled well-child appointments. Your PCP is the primary contact for your child's medical and non-medical needs.

Early Intervention Professionals are available to help you and your child with development support. You should begin working with these professionals as soon as you receive your child's diagnosis. They can help your child avoid language delays. Iowa's early intervention service provider is Early ACCESS. Early ACCESS services are provided by Area Education Agencies at no cost to you. These services may include a teacher of the deaf or hard of hearing. This teacher may help your family learn sign language or other communication strategies.



Typically, your child's audiologist or primary care provider will make a referral for Early ACCESS services. You may also contact Early ACCESS directly to start services. In addition, speech pathologists and other community-based or private providers are available. Ask your primary care provider about these additional service providers.

Otolaryngologists (also called ear, nose, and throat doctors or ENTs) will discuss your child's ear health. These doctors may investigate possible middle ear health and medical issues causing your child's hearing loss. An ENT's approval or medical clearance is required in order to receive hearing aids for medical reasons. Your ENT will provide information about your child's general medical condition before communication choices are made. For some children, this may include other conditions that are linked to the hearing loss.



Parent connections are an important part of any support team. Hearing loss can affect you and your whole family. You may have concerns, frustrations, and needs that only another parent will understand. Connecting with other parents who share this experience can be very important. Families can find support from many sources: Formal and informal parent support groups; Mentors or role models; Professionals; Family, friends, and neighbors; and Information from websites, books, and brochures. Across Iowa, ASK Resource Center is one organization that provides support and feedback to families of children who are deaf or hard of hearing.

Language and Communication

Learn what to expect and how you can help your child.

The first three years of life, as the brain develops and matures, is the most important period for learning speech and language skills. These skills best develop in a world that is full of sounds, sights, and consistent exposure to the speech and language of others. This time is very important for speech and language development. If this period passes without exposure to language, it will be more difficult to learn. Learning language is more than making sounds. Listening, understanding, and knowing the names of people and things are all part of language development.

It is important to discuss how you want your child to communicate with the world around him or her. Fortunately, there are many options for helping your child become an active participant with family members, friends, and others. It is very important to develop a communication strategy as soon as possible in order to make language learning easier.

Your child's brain is...



50% developed at 1 year



80% developed at 3 years¹

Receptive language

is the ability to understand spoken, signed or printed language.



Expressive language

is the ability to put thoughts into words or signs.

What is language?

Each child's ability to express himself (expressive language) and understand others (receptive language) is different. Communication options are available, no matter your child's language comprehension level.

Communication strategies for children with **receptive language difficulties** may include: Hearing devices (such as bone-anchored or standard hearing aids); Signing systems; Cueing systems such as phonetic signs or pictures; and Object/picture exchanges to represent or express a word (for children with vision concerns).

For **expressive language difficulties**, strategies may include: Spoken word; Cued speech; Signed language; and Signing systems. Research the strategies and discuss them with your support team.

Language Milestones

Hearing loss can affect your child's ability to develop language. Comparing how your child is communicating with other children is a good way to track your child's development. It is important to know that communication skills begin developing before your child speaks his or her first word. From birth to 3 years is the most critical period for learning language. Language problems during that time may affect social and educational development later.

Early language intervention can allow your child to be a more successful communicator as he or she grows.

Birth-3 Months



- Quiets or smiles when spoken or signed to
- Increases or decreases sucking behavior in response to sound
- Makes pleasure sound (cooing, gooing)



Under 4-6 Months

- Moves eyes in direction of sounds or signs
- Responds to changes in tone of voice
- Chuckles and laughs
- Makes gurgling or babbling sounds when left alone and when playing with you
- Uses body language to indicate when something is heard or seen (turns head, smiles, widens eyes, stops action, quiets, makes facial changes)
- Searches to find the source of a sound
- Watches a speaker's face

Under 7-12 months



- Listens when spoken to
- Recognizes word for common items such as 'cup' or 'shoe'
- Uses speech and non-crying sounds to get and keep attention
- Uses one or two words
- Attends to person speaking or signing
- Uses sign babbling (not true sign) or may try one word signs (not always correctly)
- Responds appropriately to non-verbal communication
- Understand simple requests

For More information Visit:

<http://www.asha.org/public/speech/development/chart;>
<http://www.cdc.gov/ncbddd/actearly/milestones/>

¹Gilmore JH, Lin W, Prasatwa MW, et al. Regional gray matter growth, sexual dimorphism, and cerebral asymmetry in the neonatal brain. Journal of Neuroscience. 2007;27(6):1255-1260. <http://www.urbanchildinstitute.org/why-0-3/baby-and-brain>