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A PARENT'S GUIDE TO DEAF AND HARD OF HEARING EARLY INTERVENTION RECOMMENDATIONS

2017

Developed by the Early
Hearing Detection &
Intervention Parent to
Parent Committee

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"How do we know if our child is receiving the right services?"

Many parents ask this question when they first get the news that their child is deaf or hard of hearing (D/HH) and are setting up needed services for the first time. We know because we, as parents, asked these same questions in the beginning of our own journeys. Caretakers just starting out need so much information. This document offers guidelines so that you and your child will receive the most appropriate services, no matter where you live.

In 2013, the Joint Committee on Infant Hearing (JCIH) created twelve goals to supplement the Early Intervention Recommendations outlined in their initial 2007 statement. The Supplement* defines quality early intervention and how you can better recognize recommended practices in the services provided to your child.

The national Early Hearing Detection and Intervention (EHDl) Parent to Parent Committee developed this guide to communicate directly with parents. You can use this Guide to understand what you have the right to expect in Early Intervention.

About this Guide

This Parent's Guide was developed by the Early Hearing Detection and Intervention (EHDl) Parent to Parent Committee, which is made up of parents of children who are deaf or hard of hearing as well as a diverse group of professionals who support families in EI and beyond.

*About the Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention after Confirmation That a Child Is Deaf or Hard of Hearing

This Early Intervention (EI) services document was drafted by teams of professionals with extensive expertise in EI programs for children who are deaf or hard of hearing and their families. The team used literature searches, existing systematic reviews, and recent professional consensus statements to develop a set of guidelines.

These comprehensive guidelines help EHDl programs establish strong Early Intervention systems with expertise to meet the needs of children who are deaf or hard of hearing. For the infant or young child who is D/HH to reach his or her full potential, families and professionals must work together quickly to build carefully designed individualized intervention in a family's home and community. This includes engaging service providers with optimal knowledge and skill levels that fit the diverse needs of this population.

The Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention after Confirmation That a Child Is Deaf or Hard of Hearing can be found here: <http://pediatrics.aappublications.org/content/131/4/e1324>

Below are the twelve goals outlined in the JCIH Supplement. For each goal we explain what the goal means and provide considerations as you reflect on your family's own experience and needs for your child.

This Guide can help you:

- Help you understand best **practices** for Early Intervention (EI)
- Help you assess your EI services based on the standards recommended by the JCIH
- Empower your family to advocate for appropriate EI services
- Improve partnerships between families and professionals to help children receive best practices in EI Services

Acronyms you will see in this document:

D/HH – Deaf or Hard of Hearing

EHDI – Early Hearing Detection and Intervention

EI – Early Intervention

IFSP – Individual Family Service Plan

JCIH – Joint Committee on Infant Hearing

THE GOALS, WHAT THEY MEAN AND NEXT STEPS

Let's look at each Goal in the recommendations to see what it means for children and families. For each of the 12 Goals you'll find:

- **Goal:** Original statement of the goal as it appears in the JCIH Supplement
- **What this means to me:** Brief outline of what the goal means to families
- **Things to think about:** Ideas about what families have a right to expect in Early Intervention and some further resources

1 ■ Timely and coordinated entry into Early Intervention programs

Goal

All children who are deaf or hard of hearing (D/HH) and their families have access to timely and coordinated entry into Early Intervention programs supported by a data management system capable of tracking families and children from confirmation of hearing loss to enrollment into Early Intervention services.

What this means to me

Hearing screening in newborns creates an opportunity for access but it does not always guarantee the best possible outcomes.

- Early Intervention is important
- The audiologist should connect you with Early Intervention services
- A Resource Manual or guide should be available to you, as well as a representative from your EHDI system who can explain information to you

Services provided should be:

Timely:

Your child should be able to enter into Early Intervention as soon as possible after hearing loss is confirmed. Per the national guidelines, that should be by six months of age, at the latest. (If your child was identified later, he or she should enter EI as soon as possible.)

- Your child should be enrolled in an EI program within 45 days. “Timely access” in this document means:
 - » Referring to Part C/Early Intervention within seven days after the audiologist confirms the hearing loss
 - » Developing an Individual Family Service Plan (IFSP) and starting services within 45 days after your child is referred to EI

Coordinated:

The professionals caring for your child should be communicating not just with you but also with one another. You may have been asked to sign a release so that these professionals can share information with one another. Professionals will need to inform you and each other about next steps in the baby’s entry to the early intervention process.

Supported through tracking:

The goal of tracking is to ensure your child’s timely entry into Early Intervention. The way the professionals, state, and system are managing the family’s medical information should help this process.

- All “tracking” and “surveillance” must comply with privacy laws

Things to think about

I have a right to expect:

- That anyone involved with my family/child understands the timeline and will meet all target dates
- My audiologist will connect me with EI in a timely manner
- My team of service providers (Service Coordinator, Audiologist, Therapist, Deaf

and Hard of Hearing Specialist, etc.) will provide the services my child needs or will connect me with those who can

- Everyone who works with my child communicates with each other to improve services for my child

Support through tracking:

You may be asked to sign a release of information at various agencies so that they can share information with other agencies/organizations about your child. This helps to ensure that there is communication between the service providers that serve your family.

Resources:

Information Guide

- Each state should provide you with an informational guide that lists resources. It should include:
 - » Description of all EI programs and providers
 - » Websites related to deafness and hearing loss
 - » National organizations and resources for families
 - » Terms and definitions related to deafness/hearing loss
 - » Infrastructure of state resources for families and services available through part C (birth to three years of age EI services)
 - » Communication choices and things to consider
- Here are some qualities of a guide that might be important to you:
 - » Is it in your native language? Is it in a format that is easy to understand?
 - » Is it available in different languages and formats, (e.g., written, captioned video/ DVD/Web, video blog, or 3-ring binders)?

Quality information

- Your family should have access to all available resources and information should be:
 - » Accurate
 - » Well-balanced
 - » Comprehensive
 - » Conveyed in an unbiased/culturally sensitive manner

2. Timely access to Service Coordinators who have specialized knowledge and skills

Goal

All children who are D/HH and their families experience timely access to Service Coordinators who have specialized knowledge and skills related to working with individuals who are D/HH.

What this means to me

The timelines mentioned in Goal 1 are met. A Service Coordinator, who is required by law, has been connected/assigned to my family and is meeting the appropriate timelines. A Service Coordinator is the person responsible for overseeing the implementation of the IFSP and coordinating with agencies and service providers.

- I know who the Service Coordinator is and understand their role
- My Service Coordinator described their background and experience in deafness/hearing loss

Things to think about

I have a right to expect:

- That my Service Coordinator can answer my questions
- If my Service Coordinator does not have specialized knowledge and experience in D/HH treatment/services, that there is another provider on my team who does
- My Service Coordinator has provided me with information that is appropriate, balanced, and sufficient
- My Service Coordinator has shared with me my parental rights, procedural safeguards and available services within my state
- My Service Coordinator has helped the team develop and monitor the IFSP, as well as coordinate and monitor assessments and service delivery

Resources:

The JCIH Guidelines also provide a long list of topics that the identified “first contact” for parents must be able to address if parents have questions (see the third paragraph under Goal 2 in the JCIH Guidelines document: <http://pediatrics.aappublications.org/content/131/4/e1324>).

3. E.I. providers who have professional qualifications, core knowledge and skills

All Children who are D/HH from birth to 3 years of age and their families have EI providers who have the professional qualifications, core knowledge and skills to optimize the child’s development and child/family well-being.

GOAL #3a

Intervention services to teach American Sign Language (ASL) will be provided by professionals who have native or fluent skills in ASL and are trained to teach parents/families and young children.

GOAL #3b

Intervention services to develop listening and spoken language will be provided by professionals who have specialized skills and knowledge.

What this means to me

The purpose of this goal is really to “ensure that families and children have qualified providers, regardless of the approach taken to develop communication.” Goals 3a and 3b are not intended to be mutually exclusive. Rather, they describe key quality elements when providers are using spoken or visual languages.

Things to think about

I have the right to expect:

- To know my service providers’ qualifications regarding the communication options we are exploring or using
- My service provider is coaching me on how to (a) develop my child’s language skills and (b) provide a language foundation to our child in the home to know how to access resources for other communication choices if my provider is not qualified in those options
- My intervention service provider has, or is getting, the training needed to be competent in working with my child. If my provider is not able to get such training, I know I can advocate for my provider to get additional required training
- My service provider is also addressing the social and cultural needs of my family related to deafness
- I feel capable of carrying out suggestions made during a home visit and incorporating them into my daily routine
- I have been provided information about all communication choices

4. Children with additional disabilities

Goal:

All Children who are D/HH with additional disabilities and their families have access to specialists who have the professional qualifications and specialized knowledge and skills to support and promote optimal developmental outcomes.

What this means to me

Up to 40% of children who are D/HH also have other disabilities. The purpose of this goal is ensure that communication and language development are highlighted as part of the family’s services, regardless of whether the child has additional special needs.

Why is this so important? Additional special needs often affect the child's ability to access and use language.

Things to think about

I have a right to expect:

- My providers understand the potential impact of hearing loss on other areas of development
- I have access to providers who collaborate to ensure that all aspects of my child's needs are addressed
- Additional expertise is pulled in when needed to help my child achieve target outcomes
- At least one member of my team is an expert in the area of deafness
- The team of professionals includes specialized expertise in meeting the needs of my child concerning communication access and language
- My team is sensitive to any restrictions disabilities might have, but they do not underestimate my child's abilities and skills in the area of communication and language
- My areas of concern, other than hearing loss, have been addressed and referrals made to appropriate professionals
- Parent support groups are available to our family for all areas of my child's disabilities, (e.g., Autism groups)

5. Families from culturally diverse backgrounds and/or from non-English-speaking homes

Goal

All children who are D/HH and their families from culturally diverse backgrounds and/or from non-English speaking homes have access to culturally competent services with provision of the same quality and quantity of information given to families from the majority culture.

What this means to me

This goal is meant to ensure that providers are sensitive to the diverse needs of families and experienced in meeting those needs.

Providers have experience working with culturally/linguistically diverse children who are D/HH and their families. These may be families:

- For whom English is not their primary language
- Whose providers' primary language does not match the language of the family, including families whose native language is ASL

- Whose culture may differ from providers who are serving them. Information provided must be of the same quality and quantity in the native language. Also, this information must be respectful of the families' values and beliefs, as well as accessible to families.

Things to think about

I have a right to expect:

- My EI providers ensure my family's active participation. I feel comfortable providing feedback to my EI providers
- My EI providers have training in cultural competence, including training in the language and culture of people who are Deaf
- My providers show respect to my culture and language by checking with me before providing suggestions
- My provider provides materials in a language or using a method that allows me to interact
- My provider should also be trained on beliefs about being Deaf/hard of hearing not as a disability, but as a cultural and linguistic difference
- My family-to-family support systems allow me to interact in my home language and culture
- Early Intervention services are provided in my home language
- Despite cultural or language differences, I have a clear picture of how my child is progressing
- I have the right to expect my interpreters/translators are qualified and competent in ensuring effective communication between my provider and our family. My provider will explain concepts in a way that matches my learning style to meet the goals for my child

6. All children should have their progress monitored every six months

Goal

All children who are D/HH should have their progress monitored every six months from birth to 36 months of age, through a protocol that includes the use of standardized, norm-referenced developmental evaluations, for language (spoken and/or signed); the modality of communication (auditory, visual, and/or augmentative); social-emotional and cognitive issues; and fine and gross motor skills.

What this means to me

- This goal is meant to ensure that what we are doing in intervention is working. Children should be assessed at least once every six months from birth to

36 months of age. “Progress monitoring” means your child’s language, communication, and other skills will be checked by a professional. The professional will use standard tools to measure your child’s progress. The goal is to be sure your child’s language and other developmental skills are appropriate for their age and potential.

Things to think about

I have a right to expect:

- My subjective or intuitive assessments (my “sense” or “hunches”) about my child are also being valued in this process
- What we are doing is working and we are heading towards the goals we have for my child
- I will know if our expectations are appropriate or if we need to “raise the bar”
- We are making good decisions based on assessment information
- Progress monitoring is used to prevent delays, not just correct them
- No gaps in services, assessments and progress
- We are not going backwards nor falling behind; that, in fact, my child is making regular progress
- We are looking at the whole child, not just language, but also social and emotional progress. We are getting a picture of all aspects of my child and not just one particular area of development
- My provider will explain the developmental progress my child has made, so we can make decisions together
- The standard tools used will be fair and take into consideration my child’s communication modalities and cultural differences
- My child’s EI provider uses state-adopted or -recommended assessment tools (best practices)

7. ■ Monitoring for children who are identified with hearing loss of any degree

Goal:

All children who are identified with hearing loss of any degree, including those with unilateral or slight hearing loss, those with auditory neural hearing loss (Auditory Neuropathy), and those with progressive or fluctuating hearing loss receive appropriate monitoring and immediate follow up intervention services where appropriate.

What this means to me

This Goal is intended to ensure no families “fall through the cracks.”

Children with any type of hearing loss are at risk for delays in language development, psychosocial skills, literacy development and/or communication, including speech and visual language. Families whose children have these types of hearing loss should receive:

- Appropriate monitoring of audiologic and communication development by an audiologist and/or early intervention provider. Monitoring should be consistent and frequent
- Immediate, appropriate early intervention services as follow-up

The earlier children get these services the better. Children who receive early intervention sooner may have better outcomes. “Consistent and frequent” monitoring means:

- every six months during the infant and toddler period (ages birth to 36 months)
- every 12 months thereafter

NOTE: Each child's situation may change. Collaboration between providers and with the family is important to notice changes and adjust the plan.

Things to think about

I have a right to expect:

- Hearing tests and other developmental assessments occur at regular intervals, or when I believe there has been a change in my child's hearing
- The audiologist doing the testing will explain the type of hearing loss and any changes since the last test
- I can identify the professionals who can help me ensure that regular monitoring occurs (for example, physicians and audiologists and EI providers.)
- If my child is not eligible for EI services, I know who to contact for follow up services or if my child develops delays. Appropriate information about amplification is provided if I am considering amplification for my child
- Information is available on all amplification and visual communication options in order to make an informed choice, regardless of type or degree or permanence of hearing loss
- Comprehensive information is available on the following topics, regardless of my child's current hearing status, degree or type:
 - » Possibility/probability of change in future hearing status
 - » Impact of hearing loss and otitis media on my child's daily life
 - » Amplification
 - » Communication, including information about visual communication
 - » The importance of other evaluations, including medical, vision (ophthalmologic), genetic and heart (cardiac)

- The educational information shared with my family is not limited by my child's circumstances. For example, assumptions should not be made about communication choices for a family with a child who has 'only a unilateral hearing loss.' I have ready access to information and counseling about my child's hearing status and how it might impact my child's daily life and communication development.
- I can find out what effects we might expect now and in the future
- I will be told what to look for between tests and visits with professionals
- If my child is enrolled in early intervention, the EI team is monitoring the developmental milestones and sharing that information with me. I can use this information to evaluate my child's progress
- If my child does not meet eligibility requirements for EI, I still have access to other sources of help. Some examples may include professional services, parent support groups, or Deaf/hh mentors
- I should get a clear explanation of how my child's eligibility for services was determined. Why was my child determined "eligible" or "not eligible"?
- My primary care physician has a good understanding of the process I am going through and the importance of regular visits with audiology and early intervention

8. Families will be active participants at the state/territory and local levels

Goal

Families will be active participants in the development and implementation of EHDI systems at the state/territory and local levels.

What this means to me

My experience as a parent is valuable in shaping services for other families, too. Families are encouraged to be involved in improving the systems designed to help all children who are deaf or hard of hearing. This could be at either at the local or state level.

Things to think about

I have the right to expect:

- Parents are represented on boards or committees and I have the opportunity to participate if I choose to do so
- My feedback is considered by those who design programs
- Resources are available for me to obtain the necessary knowledge and skills to take part in shaping the EHDI system
- I know who to talk to about locating these opportunities

9. Access to other families who have children who are D/HH

Goal

All families will have access to other families who have children who are D/HH and who are appropriately trained to provide culturally and linguistically sensitive support, mentorship, and guidance.

What this means to me

It is important that families have the chance to receive support from other families who have children who are D/HH and have “been there.”

Since hearing loss in children is not common, I may need help in finding other families. It is important for me to know I’m not alone. This support may include opportunities to communicate in both formal and informal ways (for example, in person, online, on the phone) Support models could be:

- Formal programs in which trained parents and families provide systematic, knowledgeable support to other families
- Informal matching of families in a given community by professionals who know other families with a similar story

Things to think about

I have the right to expect:

- Professionals working with my family will:
 - » Help me connect with other parents through either formal or informal methods
 - » Share information on local and national parent organizations
- If there is a formal system in my state, then the parents who are offering me support will be trained to:
 - » Work with families in an unbiased and appropriate manner.
 - » Respect my family’s culture and language and the communication decisions I have made for my child
 - » Know about available resources
 - » Partner with me in my journey, in a non-judgmental, non-directive manner
- If there is not a formal system in my state, then I:
 - » Feel confident in asking my professional team members to connect me with other parents and/or parent support organizations
 - » Know where to find supports online, such as social networks
 - » Feel comfortable providing feedback to my providers about the quality of my interactions

- » Feel comfortable asking my providers to help me evaluate the information I have received from informal sources of support

10. Individuals who are D/HH will be active participants in the development and implementation of EHDI systems

Goal

Individuals who are D/HH will be active participants in the development and implementation of EHDI systems at the national, state/territory, and local levels; their participation will be an expected and integral component of the EHDI systems.

What this means to me

Individuals who are D/HH are valuable in shaping services for all families. Their involvement is essential in improving the systems designed to help children who are deaf or hard of hearing. This could be at either at the local or state level.

Things to think about

I have the right to expect:

- Adults who are D/HH have meaningful roles on boards and/or committees.
 - » This includes adults with a wide range of communication experiences, life perspectives, and educational backgrounds
- That there are professional adults who are D/HH within the EHDI system and I know how to contact them
- I can advocate with local, state or national EHDI systems to include D/HH participants in their advisory or planning groups

11. Support, mentorship, and guidance from individuals who are D/HH.

Goal

All children who are D/HH and their families have access to support, mentorship, and guidance from individuals who are D/HH.

What this means to me

Individuals who are D/HH bring unique, diverse perspectives to families new to this journey. They demonstrate that D/HH individuals can be successful and have different jobs and careers. They are able to provide me with resources that I may not be aware of and give me encouragement and understanding.

As I decide about communication and language, D/HH individuals can serve as models for differing choices and opportunities and help guide me in this process. I can benefit from contact with D/HH individuals who represent the diversity of communication and language, culture, technology use, life experience and education. D/HH individuals are able to answer questions about what my child's life might look like in the future, related to school, work, relationships, family/sibling dynamics, and the "fun stuff" of life!

Things to think about

I have the right to expect:

- Professionals who work with our families will:
 - » Help me connect with individuals who are D/HH either through formal or informal methods
 - » Share local and national organizations that offer interactions with D/HH individuals
- If there is a formal system in my state, then the D/HH individuals that I am receiving support from will be trained to:
 - » Work with families in an unbiased and appropriate manner
 - » Respect my family's culture and language and the communication decisions I have made for my child
 - » Be knowledgeable about resources available
 - » Partner with me in my journey, in a non-judgmental, non-directive manner
- If there is not a formal system in my state, then
 - » I feel confident in asking my professional team members to connect me with D/HH individuals and/or organizations
 - » I know where to find supports online, social networks, etc.
 - » I feel comfortable providing feedback to my providers about the quality of my interactions
 - » I feel comfortable asking my providers to help me evaluate the information I have received from informal methods of support

12. Best practices are applied in the implementation of the intervention children and families receive.

Goal

As best practices are increasingly identified and implemented, all children who are D/HH and their families will be ensured of fidelity (i.e. reliability) in the implementation of the intervention they receive.

What this means to me

All children who are D/HH deserve the highest quality of services and resources to ensure that the child can reach his or her full potential. My child's program(s)/ provider(s) have made a commitment to providing recommended services and implementing best practices in a transparent manner as outlined in these guidelines.

These services our family receives should result in our ability to implement what we have been taught, and to see an improvement in our child's outcomes as a result of early intervention.

Things to think about

I have the right to expect:

- That the program(s) my child is enrolled in has provided me with a written description of the elements of the intervention
- My child's program will follow state laws regulating the required elements of EI
- That there are checks and balances to ensure that high-quality providers are available
- I will receive a copy of my rights as a parent and an explanation of those rights
- I have an opportunity to give input on what I have learned and how effective my services have been in my child's development
- That I will receive information about my providers' background and experience
- The opportunity to participate actively in early intervention
- My child's program uses current research to inform best practices

If you have any questions about this document, or want further explanation of its terms or content, contact www.handsandvoices.org (Click on your state on the map for state-specific support) or contact parentadvocate@handsandvoices.org