

# Early Hearing Detection and Intervention

## System Self-Assessment

Based on 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 \*

### PURPOSE:

EHDI partners and programs are committed to implementing continuous quality improvement, yet may have difficulty prioritizing where to start or how to define and measure the various dimensions of quality that improve EHDI early intervention systems. In 2013, the Joint Committee on Infant Hearing utilized literature searches, existing systematic reviews, and professional consensus statements to develop general criteria for best practices in early intervention for children who are deaf and hard of hearing (Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing).

Although these guidelines describe best practices in early intervention, they do not specify the exact means to identify where an organization might be in terms of achievement nor do they guide the stages of moving toward higher levels of quality. The ongoing use of an EHDI system self-assessment can provide a tangible means of guiding the quality drive and align partners in EHDI system improvement.

### SUGGESTIONS FOR APPLICATION:

This tool was designed to assist leaders who are responsible for Early Intervention Systems after Confirmation that Children are Deaf or Hard of Hearing. The tool is intended to be used as an assessment of a state's full EHDI system as opposed to a specific program, agency or entity. Therefore, this assessment is best completed by a team of state stakeholder, in partnership with the EHDI community and family leaders (e.g. an EHDI Advisory Committee).

In order to assure enough time for meaningful conversation, it may be best to prioritize which JCIH Goals will be addressed first. It is also possible that the Individual goals could be assigned to an Advisory subcommittee consisting of the various stakeholders who provide/receive service around that particular goal. The subcommittee would then bring the research/discussion around the goal back to the larger group for further discussion and to determine next steps.

Together stakeholders should:

1. Review Goal introduction from JCIH in order for the group to understand the purpose, scope and intent of the goal. Together determine how the group will define terms.
2. Discuss each item under the group. Put a check in the box pertaining to the level of development for each component.
3. After reviewing all components, go back to the beginning and identify your priorities and next steps.

For each question in the self-assessment tool, you will see response options based on four levels of system capability. (see Table 1). It is not uncommon for systems, even successful ones, to be at relatively low levels in certain areas.

**Table 1.**

<b>Capability Levels</b>	<b>Description</b>
1 - Nothing in Place	The EHDI system has not yet begun to address this component.
2 – Just Beginning	The EHDI system for this component is at an early stage or period.
3 – Making Good Progress	The EHDI System for this component has made satisfactory development, growth, or advancement.
4 – Established Practice	The EHDI System for this component conforms to accepted standards.

**\*Please refer to the following document for further descriptions, benchmark recommendations and information about each JCIH Goal.**

[Supplement to the JCIH 2007 position statement: Principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing. Pediatrics, 131\(4\), e1324 -e1349. doi:10.1542/peds.2013-0008](#)

<b>JCIH Goals:</b>		<b>Priority</b>
<b>1</b>	All Children Who Are D/HH and Their Families Have Access to Timely and Coordinated Entry Into EI Programs Supported by a Data Management System Capable of Tracking Families and Children From Confirmation of Hearing Loss to Enrollment Into EI Services	

2	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	
3	All Children Who Are D/HH From Birth to 3 Years of Age and Their Families Have EI Providers Who Have the Professional Qualifications and Core Knowledge and Skills to Optimize the Child's Development and Child/Family Well-being	
4	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	
5	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	
6	All Children Who Are D/HH Should Have Their Progress Monitored Every 6 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, Cognitive, and Fine and Gross Motor Skills	
7	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	
8	Families Will Be Active Participants in the Development and Implementation of EHDI Systems at the State/Territory and Local Levels	
9	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	
10	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	
11	All Children Who Are D/HH and Their Families Have Access to Support, Mentorship, and Guidance From Individuals Who Are D/HH	
12	As Best Practices Are Increasingly Identified and Implemented, All Children Who Are D/HH and Their Families Will Be Ensured of Fidelity in the Implementation of the Intervention They Receive	

Goal 1: All Children Who Are D/HH and Their Families Have Access to Timely and Coordinated Entry Into EI Programs Supported by a Data Management System Capable of Tracking Families and Children From Confirmation of Hearing Loss to Enrollment Into EI Services

**Rationale\*:**

Screening hearing in newborns creates an opportunity but it does not guarantee optimal outcomes. Timely access to quality EI providers is a critical component of a successful system. The Colorado EDHI program is an example of a program that has been able to collect comprehensive outcome data due to the implementation of EI and a consistent EI program (eg, criteria for selection of EI providers, professional development through in service training and mentoring, a standard protocol of developmental assessments at regular intervals). The Colorado EHDl system was established in 1992 and focused on timely and coordinated access to EI with statewide data management to ensure follow-through. Beginning in 1995 and continuing to the present, a series of articles on the Colorado system was published. These studies had over 500 different infant participants who were D/HH, who had no additional disabilities, and who had hearing parents. The studies included longitudinal data on 146 children from infancy through 7 years of age. Almost all were early identified and had timely access to an appropriate and consistent EI system. <sup>12</sup> On average, these children achieved age-appropriate developmental outcomes not only in the first 3 years of life<sup>10,13-16</sup> but through age <sup>79,17,18</sup> (Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2001). Other studies provided support for these findings,<sup>19,20</sup> but only the Moeller study,<sup>8</sup> published before establishing universal newborn hearing screening, studied children from a consistent EI services program.

Part C of the IDEA requires that infants and toddlers with disabilities receive EI services from birth to age 3 years. These services are provided according to an individualized family service plan (IFSP). A barrier to the development of comprehensive systems for children who are D/HH is the lack of coordination between local and state part C programs, state EHDl programs, and existing systems for children who are D/HH. To accomplish goals for monitoring and tracking children who are D/HH, a strong partnership with part C will be necessary at the national, state/territory, and local levels. At the current time, tracking systems from universal screening to confirmation that a child is D/HH, to enrollment in EI, and to developmental outcomes are being developed in many states/territories, but there are currently only a few coordinated systems.<sup>7</sup>

Loss to documentation and loss to follow-up rates are threats to the effectiveness of EHDl systems. Reduction in these losses is a high priority to strengthen the development of EHDl systems. Continuously updated data reported to the CDC indicate that a significant number of referrals lack documentation of confirmatory audiologic evaluations and/or enrollment in EI. It is estimated that currently only 1 in 4 children who are D/HH are successfully tracked to an EI system.<sup>7</sup> Loss to documentation and ineligibility for services (eg, infants with unilateral hearing loss in some states) also may contribute to loss to follow-up rates.

		Nothing in Place 1	Just Beginning 2	Making Good Progress 3	Established Practice 4	Priority?
1.1	<b>Share a baseline analysis of EHDl follow-up statistics with part C to establish collaboration and to identify system gaps or needs regarding statistics to be reviewed, such as (1) confirmation/identification of children who are D/HH and (2) their enrollment in EI services.</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.2	<b>Develop a mechanism that ensures family access to all available resources and information that is accurate, well-balanced, comprehensive, and conveyed in an unbiased manner.</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Goal 2: 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**

**Rationale\*:**

The service coordinator is the person responsible for overseeing the implementation of the IFSP and coordinating with agencies and service providers. This person is generally the first point of contact for families. The service coordinator assists families in gaining access to services; facilitates the child and family in receiving information about their rights, procedural safeguards, and services available within their state; coordinates assessments; facilitates and participates in the development of the IFSP; and coordinates and monitors the delivery of services.

Optimally, the first contact with the family should occur within days of the audiologic confirmation, and the goal should be no later than a week after confirmatory testing. The individual with first contact needs specialized knowledge and experience that include infancy/early childhood, educational strategies for infants/toddlers who are D/HH and their families, parent counseling (especially adjustment counseling specific to families with children who are D/HH), development of signed and spoken language, and auditory, speech, cognitive, and social-emotional development.

Individuals who make first contact must be able to answer parents' questions about deafness and hearing loss and provide support in understanding technical concepts including the following: screening technologies; audiologic diagnostic evaluations; amplification choices; communication choices; communication development from infancy through early childhood, including language, auditory, speech, signing, and social-emotional domains; resources relevant to working with infants/toddlers who are D/HH; medical details such as likelihood of progression of or improvement in hearing levels; and auditory/visual technology (eg, frequency modulation systems or "FM" systems, light systems, doorbells, or captions).

When parents/caregivers/families receive support from professionals who are knowledgeable about infants/children who are D/HH and their families, emotional bonding between parents and infants may be facilitated. Parental stress similar to that in hearing parents is possible and parental acceptance is more likely (Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2001).<sup>22-26</sup> Service coordinators in the Colorado EI program were specialists in EI services for families who have children who are D/HH. Studies examining outcomes of the Colorado EI program were descriptive studies and could not examine whether a causal relationship exists between provider expertise and these social-emotional characteristics. However, the studies did reveal that a program with specialized service coordinators and EI service providers is related to positive family and child social-emotional outcomes. In addition, there is evidence in the literature that some parents experience negative emotions when service coordination is provided by individuals without the core knowledge and skills for working with children who are D/HH.<sup>27</sup>

		Nothing in Place 1	Just Beginning 2	Making Good Progress 3	Established Practice 4	Priority ?
<b>2.1</b>	Develop or adapt qualifications for service coordinators who contact families after confirmation that their child is D/HH.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>2.2</b>	Identify the core knowledge and skills for service coordinators on the basis of evidence-based practices and the recommendations of professional organizations and national policy initiatives.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>2.3</b>	Identify the number and percentage of families who had timely access to a service coordinator with skills and expertise related to children who are D/HH and their families.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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## Goal 3: All Children Who Are D/HH From Birth to 3 Years of Age and Their Families Have EI Providers Who Have the Professional Qualifications and Core Knowledge and Skills to Optimize the Child’s Development and Child/Family Well-being

### Rationale\*:

States/territories need to ensure that EI providers meet at least minimum criteria for experience and skills necessary to serve infants who are D/HH and their families. Because of the shortage of qualified professionals, it is important that a system for building capacity exists at the preservice, in-service, and mentoring levels. A primary goal of the EI program is to promote children’s development of strong language skills, regardless of the route or routes taken by the family (eg, spoken language, American Sign Language [ASL], visually supported spoken language). This goal is critical because it is widely recognized that well-developed language skills serve as a foundation for communication and literacy attainment.<sup>28</sup> Goal 3 (and Appendix 1) promotes reliance on qualified providers, and recommends processes for ensuring that families access them. 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. Systems that manually code or cue spoken language are not included in goals 3a or 3b because they are not distinct languages. However, when these approaches are implemented by families, the same competencies described below apply. The purpose of goal 3 is to ensure that families and children have qualified providers, regardless of the approach taken to develop communication.

The purpose of these recommendations is to assist states and territories in the provision of high-quality EI through

- identification of the core knowledge and skills for direct EI services providers (eg, those who provide developmental, educational, and communication/language [including spoken and/or sign language] services; see Appendix 1);
- development of guidelines for the delivery and evaluation of a system of ongoing professional development for direct EI service providers.

Recent research suggests that outcomes for young children and their families are better when providers have specialized training specific to working with infants and toddlers who are D/HH and their families, although more evidence is needed.<sup>8,9,19,29-31</sup> Professional consensus statements acknowledge the need for service providers with specific training in serving children who are D/HH.<sup>32,33</sup> A survey of specialists from 17 organizations with interests in the area of EI for children strongly supported the need to identify a set of core competencies for EI specialists working with children who are D/HH (M. Sass-Lehrer, A. Stredler-Brown, M.P.M., unpublished data, 2008).

EI providers have a wide range of disciplinary backgrounds<sup>34</sup> and may not have sufficient preservice course work and/or practicum experiences that address the needs of children who are D/HH from birth to age 3 years and their families. As a result, they may lack core knowledge and skills to work with this population effectively (M.V.Compton, J.A. Niemeier, E. Shroyer, unpublished data, 2001; M. Sass-Lehrer, A. Stredler-Brown, N. Hutchinson, K. Tarasenko, M.P.M., K. Clark, unpublished data, 2010).<sup>35-38</sup>

Approximately one-third of all states in the United States have a professional certification or credential that includes children who are D/HH from birth to age 3 (M. Sass-Lehrer, A. Stredler-Brown, N. Hutchinson, K. Tarasenko, M.P.M., K. Clark, unpublished data, 2010). However, the standards vary widely and may not specifically include course work and field experiences that address the needs of infants and toddlers who are D/HH and their families.

At most institutions specific to children who are D/HH, the wide range of disciplinary backgrounds and limited preservice training opportunities create a need for systematic capacity building. For the various disciplines working with children who are D/HH, appropriate professional development guidelines that support theory and evidence-based practice must be established. Evaluation of training and training outcomes is essential, because the quality of the professional training is ultimately reflected in the impact on child and family outcomes. Wide variations in the skills of the providers and the developmental outcomes of children who are D/HH exist throughout the United States and its territories. Personnel development guidelines need to be in accordance with the existing legal requirements of part C of the IDEA<sup>4</sup> and with the requirements in each state or territory (eg, credentials or qualifications for EI specialists).

Nothing in Place 1	Just Beginning 2	Making Good Progress 3	Established Practice 4	Priority ?
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3.1	Adopt and implement guidelines that address the professional qualifications required for providing family-centered EI to families and children who are D/HH from birth to age 3. These guidelines will address educational background and core knowledge and skills for providers of EI services in areas, including developmental, educational, and communication/language.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.2	Ensure that stakeholders participate in the adoption and implementation of these guidelines. Stakeholder categories will include, at minimum, the state EHDl and part C programs, EI direct service providers with core knowledge and skills serving children who are D/HH from birth to age 3, parents/caregivers with children who are D/HH, and adults who are D/HH with a background in a related area..	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.3	Provide the resources needed for professionals to obtain the core knowledge and skills to serve children who are D/HH from birth to age 3 and their families.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.4	Following the approved guidelines, identify the number and percentage of EI providers who have the appropriate core knowledge and skills and who are currently providing services to families with infants/children who are D/HH. Consider recruiting experienced professionals to mentor others (eg, via distance technology or onsite visits).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.5	Following the approved guidelines, identify the number and percentage of EI providers who have the appropriate core knowledge and skills and who are currently providing services to families with infants/children who are D/HH. Consider recruiting experienced professionals to mentor others (eg, via distance technology or onsite visits).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.6	Regularly monitor progress toward this goal by annually identifying the number of families who are receiving EI services from professionals with core knowledge and skills as determined by the state-developed qualification system.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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## Goal 3a: Intervention Services to Teach ASL Will Be Provided by Professionals Who Have Native or Fluent Skills and Are Trained to Teach Parents/Families and Young Children

### Rationale\*:

A system of highly qualified EI service providers must be available for all families across the spectrum of communication choices. An area that has been particularly deficient for families who choose ASL is access to an EI provider who is a fluent/native ASL signer<sup>39,40</sup>.

Families with children who are D/HH in the process of learning ASL require access to competent and fluent language models. In EI systems, competency and fluency are not ensured among EI providers. To establish the basic grammatical foundations of visual language learning for a newborn infant who is D/HH, access to competent and fluent language models is vital.<sup>41,42</sup> However, although fluency of the language model is necessary, it is not sufficient to make a professional qualified to provide EI services. Families with children who are newly identified also need information and resources from EI professionals on how to provide an enriched language environment that supports their child's early language learning. As an example, the SKI-HI Institute Deaf Mentor program is a model that can provide resources and training for people who are D/HH to support a family's learning of ASL. The families can be given resources and support in acquiring ASL through collaboration with professionals who are D/HH and who communicate in ASL. In SKI-HI's Deaf Mentor program, adults who are D/HH are role models for the young child and family members. The child and the family learn ASL and are introduced to various deaf culture events. The SKI-HI Institute conducted a 3-year study entitled "The Deaf Mentor Experimental Project for Young Children Who Are Deaf and Their Families," and found that children of hearing parents who are exposed to a bilingual and culturally competent environment through Deaf Mentor services have positive outcomes. Not only did the children have a beginning knowledge and use of ASL but they were also developing English skills at a faster rate than children who did not receive Deaf Mentor services and received services solely from a SKI-HI parent advisor.<sup>40</sup>

		Nothing in Place 1	Just Beginning 2	Making Good Progress 3	Established Practice 4	Priority ?
<b>3.1a</b>	Ensure that families have complete and accurate information about ASL.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>3.2a</b>	Identify collaborative partners who can assist in the development of statewide systems capable of providing competent sign language instruction to families and their infants/children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>3.3a</b>	Establish a representative committee that develops guidelines related to the qualifications of sign language instructors.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>3.4a</b>	Conduct a needs assessment to determine (1) the number of available sign language instructors with the qualifications in sign language and family/infant education and (2) available funding sources.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>3.5a</b>	Develop systems that ensure that neither geographic location nor socioeconomic status limits access to competent and skilled sign language instructors. State systems should consider utilization of all technology, including computer and videophones, to support teaching families.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>3.6a</b>	Establish and conduct training for ASL instructors that includes strategies and techniques for teaching sign language to families of infants and toddlers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>3.7a</b>	Establish a quality assurance program for ASL instructors of parents/families.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



<b>3.8a</b>	Conduct a needs assessment to determine the number of professionals (compensated or volunteer) with the qualifications and skills required to serve as an ASL instructor for families/parents of infants.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>3.9a</b>	Ensure that ASL instructors can accept, without judgment, a family's use of their sign language skills with or without spoken language.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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Goal 3b: Intervention Services to Develop Listening and Spoken Language Will Be Provided by Professionals Who Have Specialized Skills and Knowledge

**Rationale\*:**

The development of listening and spoken language skills is now attainable for the vast majority of infants/children who are D/HH (without severe additional disabilities) when they are identified early and are provided with early and appropriate EI services beginning with fitting of amplification that ensures audibility across the speech spectrum of the native spoken language.<sup>44</sup> The consensus of professionals who specialize in intervention for listening and spoken language for children who are D/HH is that these skills are frequently not mastered in typical preservice training programs of educators of the deaf, speech- language pathologists, or audiologists.<sup>32</sup>

Competent service delivery systems have a series of checks and balances, as well as cross-check processes, to ensure fidelity of intervention. For example, an EI provider should be able to share information regarding the child’s behavior and response to sound across the speech frequencies with the child’s audiologist. This information can assist the audiologist in fitting, optimizing, and verifying the child’s hearing aids. This system should ensure that maximal audibility has been provided to the child, thus offering the child optimal access to spoken language. In addition, the EI provider should be alert for changes in the infant/child’s hearing capabilities, which can occur due to permanent or medically treatable causes. These changes are most likely to be a progression of the hearing loss, although improvement and fluctuation in hearing sensitivity can also occur. EI specialists need to be able to individualize services to the child’s current auditory capabilities with their technology. In addition, the EI provider needs expertise regarding listening and spoken language developmental hierarchies and the ability to use diagnostic teaching to ensure that the auditory linguistic strategies being used are the most effective.

Research indicates that there are sensitive periods for the development of auditory skills and spoken language; specifically, the first 5 years of a child’s life are critical for development in these areas,<sup>10,45,46</sup> To optimize this short time period in a child’s life, families and infants/children who are D/HH require the highest level of provider skills at the very beginning of the child’s life.

Unfortunately, most EI systems currently provide limited access to professionals with expertise in listening and spoken language and do not collect system-wide outcome data on children’s development of listening and spoken language skills.<sup>47</sup> Such data are essential to ensure that families and children have received high-quality intervention with targeted outcomes. Many EI systems do not offer professional development opportunities to ensure continuous improvement for the EI providers, nor do they offer consultation/mentorship and/or direct observation to guarantee fidelity of the intervention implementation. These are critical areas of need if best practices in listening and spoken language are to be established.

		Nothing in Place 1	Just Beginning 2	Making Good Progress 3	Established Practice 4	Priority ?
<b>3.1b</b>	Ensure that families have complete and accurate information about listening and spoken language development.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>3.2b</b>	Identify collaborative partners who can assist in the development of statewide systems capable of providing competent listening and spoken language instruction to families and their infants/children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>3.3b</b>	Establish qualifications of EI service providers with the core knowledge and skills to develop listening and spoken language (example: Listening and Language Self-Checklist for Colorado Home Intervention Program (CHIP) Facilitators).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>3.4b</b>	Conduct a needs assessment to determine the number of available EI providers with the qualifications and skills required for developing listening and spoken language with infants who are D/HH.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>3.5b</b>	Develop systems and ensure that neither geographic location nor socioeconomic status limits access to competent EI providers with knowledge and skills in developing listening and spoken language. State systems should consider utilization of all technology, including computer and videophones, to support teaching families.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>3.6b</b>	Establish and conduct training for EI providers to increase their skills in providing listening and spoken language development.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>3.7b</b>	Establish an evaluation of the skills and knowledge of EI providers in their delivery services for listening and spoken language.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>3.8b</b>	Ensure that the EI providers have been observed sufficiently, have been provided with feedback, and have demonstrated skills in the provision of listening and spoken language interventions for families with infants/children who are D/HH.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>3.9b</b>	Ensure that EI providers can accept, without judgment, the family's use of the listening and spoken language skills they have learned with or without the use of sign language or any other visual communication system.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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Goal 4: 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

**Rationale\*:**

It is estimated from previous studies that 35% to 40% of all children who are D/HH have disabilities in addition to deafness.<sup>10,49</sup> These additional disabilities often affect the child’s ability to access and use language. Very little empirical information is available about development in the first 6 years of life for children who are D/HH with additional disabilities. However, appropriate EI services should result in similar advantages for children who are D/HH with additional disabilities as for children who are D/HH only.<sup>10,13,50</sup> Children who are D/HH, were identified before 6 months of age, and had cognitive skills ranging from quotients of 20 to 80, demonstrated significantly better language scores than did later-identified children with multiple disabilities in the first 3 to 5 years of life when they were early-identified and received timely EI services.<sup>10,50</sup>

For some children who are D/HH and have additional disabilities, it may be determined that hearing loss is not the primary disability. Regardless of the primary disability, however, it is critical to recognize the primacy of communication for learning and the impact of communicative delays on other developmental domains. Therefore, the team of professionals serving the child must include specialized expertise in meeting the communication access needs of the child.

EI specialists serving children who are D/HH with additional disabilities should be able to

- monitor developmental needs and outcomes across domains with appropriate assessments;
- recognize developmental concerns and involve a team of evaluators before attempting to design an intervention program;
- work as an effective and integrated member of a transdisciplinary team, in a manner that optimizes child and family learning;
- modify developmental strategies to accommodate the child’s special needs;
- advocate for and facilitate the parent/family understanding of medical, developmental, pediatric, and other specialty reports and their implications for the child’s learning;
- collaborate with the managing audiologist to adapt assessment and amplification approaches to accommodate the child’s special needs;
- recognize the child’s needs and make referrals for specialty evaluations (eg, feeding and swallowing, oral motor, etc);
- assist families in prioritizing needs to optimize the level of service delivery at various ages;
- adapt EI strategies to appropriately accommodate disabilities in other developmental domains and to reinforce goals of other specialty providers on the team;
- use augmentative communication devices and strategies, including individualized evaluation and implementation;
- manage mobilization devices and other supportive equipment needed by the child

	Nothing in Place 1	Just Beginning 2	Making Good Progress 3	Established Practice 4	Priority ?
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4.1	Develop and implement a data management system capable of reporting the number and percentage of children who are D/HH with additional diagnosed disabilities, including the following: visual, intellectual, or emotional/behavioral disability; fine and gross motor delays with or without cerebral palsy; autism spectrum disorder; sensory processing disorder; and craniofacial or neurodegenerative disorders or brain malformations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.2	Develop a system with the ability to track children who are D/HH with additional disabilities regardless of the primary disability of the child, identifying the individual or agency that can and will assume responsibility for tracking these children (eg, EHDI or part C, public school programs, or schools for the deaf).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.3	Ensure that the developmental monitoring protocol is adaptive and sensitive to any restrictions in performance that are due to the additional disability and that would significantly underestimate the abilities and skills of the child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.4	Implement models of transdisciplinary services, making certain that families who have children with multiple disabilities have access to EI services that meet the needs of the child and family in all developmental domains.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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Goal 5: 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

**Rationale\*:**

The number of culturally and linguistically diverse children who are D/HH in the United States and its territories is continually rising. In some major urban areas, and in some states, the number of culturally diverse occupants is now the majority. There is a rapid and growing population of children who are D/HH living in homes in which the primary language is not English. Families who use ASL as the language of communication within the home are also a culturally and linguistically diverse population. An additional aspect of diversity is the significant portion of families who have limited levels of literacy, parental education, and/or family income. These families are at high risk of failure to access and benefit from traditional educational services. However, research within the United States has revealed that it is possible to deliver EI services that result in appropriate development of children of families from culturally diverse backgrounds.[10,17,50](#)

It is important that the information provided to families is of the same quality and quantity provided to native English speakers and that it is delivered in a manner that is accessible to the families. Even when culturally diverse families are able to communicate successfully in spoken English or ASL, they may have values and beliefs that affect their understanding and acceptance of information conveyed in EI. These values and beliefs may also affect their ability or willingness to follow through on recommendations. Therefore, it is essential that the manner in which information is delivered is respectful of the beliefs and values of the families and their countries of origin.[51,52](#)

Spoken languages throughout the world have differences in phonology, semantics, syntax/grammar, and pragmatics. For a child to successfully develop spoken language skills in any language, he or she must have access to high-quality instruction in that language.[53-55](#) Thus, EI providers need to learn to adapt auditory skill development strategies for the teaching of spoken English, to the acoustic characteristics of the family’s native language if the family chooses a spoken language approach.

Like spoken languages, visual language systems are unique and differ around the world. However, unlike spoken language, many families are not knowledgeable about their native signed languages, and therefore introduction of ASL or other visual systems used in the United States is often appropriate when chosen by the family.

		Nothing in Place 1	Just Beginning 2	Making Good Progress 3	Established Practice 4	Priority ?
<b>5.1</b>	Identify the number of families who speak or sign a language other than English in the home and the percentage of families using non-English languages by native language.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>5.2</b>	Identify the number of families who speak English and are culturally diverse, including the areas of cultural diversity (African American, Hispanic/Latino, Asian American or South Pacific Islander, or American Indian/Native American).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>5.3</b>	Develop a plan for ensuring access to information for families whose native language is not English that is comparable to information provided to native English-speaking families by providing resources in the family’s home language or languages.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>5.4</b>	Ensure that families from diverse cultures participate in and feel comfortable giving feedback about services received, by providing diverse communication mechanisms including face-to-face feedback or surveys in the home language or languages), “buddy systems” and peer mentors from culturally diverse groups, community leaders who can serve as cultural brokers and advisers, and consistent interpreters who are trained in the EI curricula specific to families with children who are D/HH.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5.5	Develop professional in-service training that includes information about providing services to families who do not speak English. This training should include such topics as cultural differences in attitudes and beliefs about disability, behaviors that may be considered offensive by other cultures, avoidance of cultural stereotypes, and different cultural expectations of medical, allied health, and educational professionals. Training should also include beliefs about being D/HH not as a disability but as a cultural and linguistic difference.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.6	Monitor the developmental progress of children who are acquiring languages other than spoken English. For some of the more common languages, such as Spanish, there are a few developmental instruments that can be used. As developmental assessments become available in other languages, they should be incorporated into EI programs to assist families in monitoring their child's progress and determining whether the choices made are facilitating success in communication for their child who is D/HH.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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Goal 6: All Children Who Are D/HH Should Have Their Progress Monitored Every 6 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, Cognitive, and Fine and Gross Motor Skills

**Rationale\*:**

The current IDEA part C developmental assessment of children with disabilities is designed to demonstrate that EI services remediate developmental delay for infants/toddlers and children with disabilities. In contrast, EHDI systems have been established for the prevention or amelioration of the developmental delays often associated with children who are D/HH. Thus, developmental assessment for this population is designed to ensure that the children are mastering the developmental skills appropriate for their age and cognitive functioning. Earlier identification of children who are D/HH has been established with the goal of prevention of delay, not remediation of delay.

The urgency of providing appropriate EI services is supported by evidence of reduced and limited success of EI strategies that are initiated after the sensitive period for language and auditory development.<sup>8,10</sup> The goal of EI services for infants/children who are D/HH is to provide sufficient support to ensure that the child makes appropriate progress toward expected developmental objectives. The best opportunity to accomplish this goal is the prevention of developmental disability. Therefore, progress monitoring should be done with instruments that are norm-referenced. Assessment tools should be appropriate for the language and communication system used by the child.

Monitoring of developmental progress provides parents/families and EI providers objective data about the individual rate of their child's development and can guide their decision making. In addition, systematic monitoring of developmental progress has the potential to provide states/territories, local educational agencies, and individual early childhood programs with information that can guide system change and continuous improvement by identifying strengths and weaknesses within their system.

		Nothing in Place 1	Just Beginning 2	Making Good Progress 3	Established Practice 4	Priority ?
<b>6.1</b>	Monitor the developmental progress of all infants identified through universal newborn hearing screening (UNHS) on a consistent schedule, every 6 months through 36 months and annually thereafter, to ensure that children are making appropriate progress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>6.2</b>	Develop a statewide standard assessment protocol used with all children who are D/HH to provide the state/territory with an opportunity to do quality assurance of components of their EI system. States could develop a standard assessment battery in collaboration with experts in their state and either directly implement the battery or ensure that it is implemented (eg, in collaboration with a university, research entity, or other program capable of collecting and analyzing statewide assessment data for children who are D/HH). This information can then be use to improve the skills of the providers and the characteristics of intervention.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>6.3</b>	Develop a collaborative sharing network capable of collecting developmental data for progress monitoring at regular intervals including data reporting to the EHDI database.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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Goal 7: 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

**Rationale\*:**

Children with hearing loss are at risk of academic failure (math and reading), delayed language development, progression (worsening) of hearing loss, and/or psychosocial delays. This finding has been revealed in a number of studies over the past 35 years, in populations having all types and degrees of hearing loss.<sup>56-65</sup> Children who are diagnosed as having unilateral hearing loss may experience onset and progression of hearing loss in the formerly normal hearing ear.<sup>62,66</sup> Children with relatively lesser degrees of hearing loss may experience fluctuation/progression into the more severe ranges (Yoshinaga-Itano C, unpublished data, 2011). Children with auditory neural hearing loss (auditory neuropathy spectrum disorder) have been found to have significant delays in communication, speech, spoken and visual language, psychosocial skills, and literacy development. In general, their developmental profiles are similar to children with sensory deafness.<sup>67-69</sup>

Very little is known about the developmental outcomes of children with permanent sensorineural hearing loss who experience fluctuation due to conductive hearing losses. Children with hearing loss are at an increased risk of increased hearing loss in the presence of otitis media as compared with children with normal hearing because of the number of children with hearing loss and craniofacial anomalies or syndromes such as Down syndrome. Appropriate amplification fitting and audiologic monitoring are required for these children to maintain optimal developmental progress.

Consistent and frequent audiologic monitoring is important for all children who are D/HH, with any type of hearing loss. However, the audiologic and medical follow-up of the children in the audiologic categories covered in goal 7 are frequently initiated by the EI service provider who, in conjunction with the parent or parents/family, notices changes in the child's auditory behavior and speech/spoken language development. It is hoped that more frequent audiologic monitoring of these children will result in an earlier identification of issues such as progression, improvement, or fluctuation. EI providers need to establish close collaboration with audiologists to effectively manage these children. This need for collaboration is especially the case when the EI providers do not have specialized knowledge about the auditory skills and spoken language development of children with all types and degrees of hearing loss.

		Nothing in Place 1	Just Beginning 2	Making Good Progress 3	Established Practice 4	Priority ?
<b>7.1</b>	Refer all children with unilateral or bilateral hearing loss to EI for evaluation and consideration of enrollment. If the child does not qualify for state EI services, ensure that families are provided with access to information and counseling regarding their child's hearing loss and the potential impact of hearing loss on the child's daily life and communication development.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>7.2</b>	Develop follow-up mechanisms for ongoing monitoring of hearing, speech/language, and communication for all children with hearing levels that fall outside the range of normal in one or both ears, regardless of the etiology of the hearing loss. This monitoring should include follow-up mechanisms for children with chronic, nonpermanent conductive hearing losses.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>7.3</b>	Monitor communication development (receptive and expressive language, speech, and auditory skills) through appropriate developmental screening protocols every 6 months in the infant/toddler period and every 12 months thereafter.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>7.4</b>	Identify the agency or professional responsible for surveillance and make sure that surveillance occurs (eg, either through the medical home or managing physician, the audiologist, part C, or a referral back to the EHDI system).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7.5	Determine and designate a provider or system (eg, part C, EHDI, primary care physician, parent/family) that ensures that developmental screening of communication, audiologic monitoring, tracking, and surveillance occurs, especially if the child has been deemed ineligible for EI services through the state part C system.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.6	Develop and disseminate information about the use of amplification for children with hearing loss prepared by consulting audiologists with expertise with infants/children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.7	Provide families with an opportunity for access to visual communication, which may include sign language systems, in addition to listening and spoken language, particularly in light of the possibility/probability of progressive hearing loss.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.8	Ensure that a child with a conductive hearing loss that has persisted in the first few months of life and remains for 6 months will be referred to EI services and otologic specialty care to make sure that adequate auditory access is available to the child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.9	Consider amplification, if the hearing loss has remained for 6 months even if it is temporary, to accomplish this auditory access. This group also includes children with cleft palate or Down syndrome, who are at very high risk for chronic fluctuating middle ear effusion.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.10	Surveillance should include parent/family counseling and evaluation by a speech-language pathologist to monitor progress in speech and language acquisition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.11	Limited research suggests that children with minimal/mild bilateral hearing loss may not wear hearing aids either because (1) the children reject the amplification, (2) the parents/family are unable to promote consistent amplification usage, or (3) the parents/ family are themselves not convinced of the benefit of amplification.					
7.12	Provide educational information to parents/family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.13	Encourage primary care physicians to recognize the need for ongoing audiologic surveillance in all children, particularly those with risk factors for delayed-onset/progressive hearing loss, or those children whose hearing loss is already being treated with hearing aid amplification. This surveillance should include developmental checks consistent with the American Academy of Pediatrics Periodicity Schedule, or more frequently if concerns are raised regarding hearing or development.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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Goal 8: Families Will Be Active Participants in the Development and Implementation of EHDI Systems at the State/Territory and Local Levels

**Rationale\*:**

Equitable partnerships between families and EI programs and systems are critical to the success of EHDI programs and the achievement of optimal outcomes for children. Family leadership and involvement are critical when developing policies and programs to ensure that the systems of care support a genuine reflection of the day-to-day challenges and opportunities facing families.<sup>1</sup>

- Qualified parent/family leaders are appropriately trained on such topics as advocacy, systems building, parent/family/professional partnerships, theories of adult learning styles, and family-to-family support.
- Parent/family leaders contribute to the EHDI system by exhibiting the elements of collaboration, that is, mutual respect for skills and knowledge, honest and clear communication, understanding and empathy, mutually agreed-upon goals, shared planning and decision making, open sharing of information, accessibility and responsiveness, negotiation and conflict resolution skills, and joint evaluation of progress.
- Parent/family leaders have the capacity to look beyond their own personal experiences/beliefs to represent and support a broad community of families.

		Nothing in Place 1	Just Beginning 2	Making Good Progress 3	Established Practice 4	Priority ?
<b>8.1</b>	Develop or revise policies and legislation related to EHDI programs that require the meaningful inclusion of qualified families as active participants in the development and implementation of EHDI systems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>8.2</b>	Report the number of professional family positions (ie, compensated rather than volunteer) and demonstrate how parents and families are involved in recruitment processes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>8.3</b>	Provide resources (professional development training and mentorship) for families to obtain the necessary knowledge and skills to participate in systems and policy development and demonstrate that training is provided.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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Goal 9: 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

**Rationale\*:**

Given the low incidence of children who are D/HH, families often feel isolated and do not typically have support opportunities in their established communities. Being deaf or hard of hearing impacts the child as well as the parents, siblings, extended family, and community. No one understands this as well as other families with children who are D/HH. Families report that there is something unique and important in receiving support from other parents and families who have children who are D/HH and who have “been there.” There is a sense of an equitable relationship between the experienced parent and the referred parent that cannot be duplicated through other dynamics.<sup>73</sup>

Opportunities for families to communicate with one another, chat online, and attend support groups or other activities designed for communicating with other parents and families are a valuable component of the circle of support. National organizations such as the Alexander Graham Bell Association for the Deaf and Hard of Hearing, the American Society for Deaf Children, Family Voices, and Hands & Voices (and the Hands & Voices “Guide by Your Side” program) have models for providing family-to-family support. Support models range from formalized programs in which trained parents/families provide systematic, knowledgeable support to the informal matching of families in a given community by professionals who know other families with a similar story.

Families rank family-to-family support as one of the most helpful forms of support for the family.<sup>27,74</sup> Parents/families reporting participation in social networks with other parents/families of D/HH children had less isolation, greater acceptance of their child, and improved interactional responsivity.<sup>75</sup>

		Nothing in Place 1	Just Beginning 2	Making Good Progress 3	Established Practice 4	Priority ?
9.1	Develop and implement guidelines that address family-to-family support. These guidelines should outline the background and training necessary for family support providers to interact with families of infants/children newly identified as D/HH, including the importance of objective, unbiased information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.2	Provide the necessary training for families/parents who participate in family-to-family support sessions and activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.3	Identify collaborative channels to create sustainable and compensated family-to-family support services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.4	Report the number and percentage of families who have had access to appropriate family-to-family supports.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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Goal 10: 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

**Rationale\*:**

Adults who are D/HH comprise a heterogeneous group of individuals with a wide range of communication experiences, careers, life perspectives, and educational backgrounds. Barriers to their inclusion in EHDI systems can be overcome when professionals acknowledge, understand, and value the importance of providing children who are D/HH and their families the opportunity to meet with adults who can share their experiences being D/HH.

The goal is to have individuals who are D/HH woven into the fabric of EHDI systems at every level. Individuals who are D/HH know what works to meet their language and communication needs in a way that people who are hearing cannot. Because the support of language and communication of infants is intended to be the heart of EHDI systems, it is critical to include D/HH adults in these systems.

Currently, few EHDI systems include D/HH adults in a meaningful way. The system should have diverse representation at many levels. D/HH persons with appropriate qualifications should be included, for example, as EHDI directors, EHDI advisory panel chairs and members, administrators, part C service coordinators, audiologists, speech-language pathologists, pediatricians, counselors, mentors, ASL teachers, EI service providers, and educators of the deaf and in other roles. To achieve these goals, EHDI systems should partner with national, state, and local organizations that support D/HH persons.

		Nothing in Place 1	Just Beginning 2	Making Good Progress 3	Established Practice 4	Priority ?
<b>10.1</b>	Develop or revise policies and legislation related to EHDI programs to require inclusion of individuals who are D/HH and who represent a diverse range of communication, educational, amplification technology, and life experiences as active participants in the development and implementation of EHDI systems (eg, involvement of such individuals in systems will be evident in recruitment processes and in the number of compensated, rather than volunteer, positions filled by individuals who are D/HH).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>10.2</b>	Implement professional development training and mentoring systems and provide the resources needed for individuals who are D/HH to obtain the necessary knowledge and skills to participate in systems and policy development.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>10.3</b>	Report the number of professional positions (eg, compensated and volunteer) filled by individuals who are D/HH at all levels of the EHDI system.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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**Goal 11: All Children Who Are D/HH and Their Families Have Access to Support, Mentorship, and Guidance From Individuals Who Are D/HH**

**Rationale\*:**

Research has revealed the benefits of providing children who are D/HH and their families connections to members of the D/HH community. Families who have many contacts with adults who are D/HH exhibit a strong sense of competence with regard to raising their child who is D/HH.<sup>75</sup> When there are no other D/HH members in the family, parents identify deaf individuals as one of the most important sources of support in addition to teachers, therapists, other parents, and spouses.<sup>76</sup> Community members who are deaf are able to provide children who are D/HH with unique perspectives that parents who are hearing cannot.<sup>77</sup>

The more interactions that families have with adults who are D/HH, the better they may envision their own child’s future, including developing goals and dreams that are not limited by misunderstandings about the lives of people who are D/HH. The goal of the system is to value infants/children who are D/HH for who they are.

Starting at the time the language and communication decision-making process begins, programs such as D/HH Connections in Colorado<sup>†</sup> involve deaf individuals in guiding, supporting, serving as role models, and interacting with the child who is D/HH and his or her family. These individuals may share personal experiences or information about being D/HH, educational and communication opportunities, using hearing technology, or about the deaf community and deaf culture. They are available to go into the home, ideally working in close coordination with other EI service providers. They may assist families in meeting IFSP goals. Providing families who are hearing with opportunities to learn more about being D/HH reduces family stress and promotes family support of the child.<sup>78,79</sup>

		Nothing in Place 1	Just Beginning 2	Making Good Progress 3	Established Practice 4	Priority ?
<b>11.1</b>	Establish an advisory group composed of a critical mass of members who are D/HH, especially those with experience with EI services and programs, along with representatives from the state EHDI system and EI providers with expertise and skill in providing services to families of infants and toddlers who are D/HH	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>11.2</b>	Make sure that the individuals who are D/HH represent the diversity of the EHDI population (eg, deaf culture, hard of hearing, cochlear implant and hearing aid users, unilateral hearing loss, auditory neural hearing loss, cultural diversity).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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Goal 12: As Best Practices Are Increasingly Identified and Implemented, All Children Who Are D/HH and Their Families Will Be Ensured of Fidelity in the Implementation of the Intervention They Receive



**Rationale\*:**

Fidelity of intervention refers to assurance that the intervention provided to the family and child is sufficient to (1) promote a good quality of life for the family and the child; (2) provide strategies for the development of spoken, signed/visual, or multimodal language that are appropriate to the family's choices and the cognitive ability and age of the child; and (3) provide strategies that optimize auditory skill development with the family's chosen technology.

High fidelity of the implementation of intervention requires (1) knowledge of intervention theory and methods, (2) well-defined interventions based on theory and methods, (3) demonstration of intervention procedures, (4) supervised practice, (5) feedback on performance, and (6) data to demonstrate that the intervention strategies result in the desired goals.

Ensuring fidelity of implementation includes the following characteristics: (1) linking interventions to improved outcomes (credibility); (2) definitively describing operations, techniques, and components; (3) clearly defining responsibilities of specific persons; (4) creating a data system for measuring operations, techniques, and components; (5) creating a system for feedback and decision making (formative); and (6) creating accountability measures for noncompliance.<sup>80</sup>

Historically, EI providers have not developed systems and programs that document the fidelity of the intervention provided to families and children. A quality EI program should have a process for continuous improvement. Therefore, it is important to establish a means of assessing and monitoring the fidelity of intervention services. This information is key to establishing an empirical evidence base for EI. Without documentation of fidelity, it is difficult to link effective interventions with successful outcomes.

EI for families and infants/children who are D/HH involves a complex interaction of many child, family, background, and intervention factors. This complexity presents formidable challenges for developing well-defined interventions, training professionals in the intervention techniques, and measuring the fidelity of these interventions. In essence, little progress has been made. Clear delineation of successful interventions is necessary to ensure replicability. However, acknowledging that we are in the infant stages of defining and measuring fidelity of intervention, it is critical that the first steps be taken.

No literature currently exists that links the fidelity of the implementation of intervention for children who are D/HH with successful outcomes. However, the extant literature reveals that assurance of the fidelity of the implementation of interventions is the key to successful outcomes for children in special education and for medical interventions for both children and adults.<sup>80-85</sup> In these studies, positive student outcomes were attributed to 3 related factors: fidelity of implementation of the process, degree to which the selected interventions were empirically supported, and the fidelity of intervention implementation (at the teacher level).

		Nothing in Place 1	Just Beginning 2	Making Good Progress 3	Established Practice 4	Priority ?
<b>12.1</b>	Develop and advance mechanisms and systems to assess and monitor the fidelity of the EI services received by families who have infants/children who are D/HH.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>12.2</b>	Identify a critical core group of experts. Trainer-of-trainer and peer mentoring models can provide a system for EI providers to receive support from professionals with the greatest experience, knowledge, and skills.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>12.3</b>	Monitor the fidelity of intervention through direct observation by a highly qualified, experienced EI provider/supervisor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>12.4</b>	Provide mentorship through input on lesson goals and planning.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>12.5</b>	Encourage and support professional development of EI providers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>12.6</b>	Conduct self-assessments of EI providers to identify their perceptions of strengths and weaknesses related to the guidelines established in GOAL 3. The goal of these self-evaluation instruments of EI providers is to identify perceived programmatic strengths and weaknesses and provide professional development in the areas of perceived weakness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>12.7</b>	Measure the progress of EI providers on their knowledge and skills at regular intervals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>12.8</b>	Obtain families' input about the skills that they have learned through EI services and their perceptions about the effectiveness of these skills in promoting successful outcomes for their children. Questions should not be about families' satisfaction but about information they have learned through EI services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

NOTES:

REFERENCE:

[Supplement to the JCIH 2007 position statement: Principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing. Pediatrics, 131\(4\), e1324 -e1349. doi:10.1542/peds.2013-0008](#)