



## STATEMENT OF ENDORSEMENT

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

**PREFACE**

FREE

This document is a supplement to the recommendations in the year 2007 position statement of the Joint Committee on Infant Hearing (JCIH)<sup>1</sup> and provides comprehensive guidelines for early hearing detection and intervention (EHDI) programs on establishing strong early intervention (EI) systems with appropriate expertise to meet the needs of children who are deaf or hard of hearing (D/HH).

EI services represent the purpose and goal of the entire EHDI process. Screening and confirmation that a child is D/HH are largely meaningless without appropriate, individualized, targeted and high-quality intervention. For the infant or young child who is D/HH to reach his or her full potential, carefully designed individualized intervention must be implemented promptly, utilizing service providers with optimal knowledge and skill levels and providing services on the basis of research, best practices, and proven models.

The delivery of EI services is complex and requires individualization to meet the identified needs of the child and family. Because of the diverse needs of the population of children who are D/HH and their families, well-controlled intervention studies are challenging. At this time, few comparative effectiveness studies have been conducted. Randomized controlled trials are particularly difficult for ethical reasons, making it challenging to establish causal links between interventions and outcomes. EI systems must partner with colleagues in research to document what works for children and families and to strengthen the evidence base supporting practices.

Despite limitations and gaps in the evidence, the literature does contain research studies in which all children who were D/HH had access to the same well-defined EI service. These studies indicate that positive outcomes are possible, and they provide guidance about key program components that appear to promote these outcomes. This EI services document, drafted by teams of professionals with extensive expertise in EI programs for children who are D/HH and their families, relied on literature searches, existing systematic reviews, and recent professional consensus statements in developing this set of guidelines (eg, refs 2 and 3; H.M. Schachter, T.J. Clifford, E. Fitzpatrick, S. Eatmon, M. Morag, A. Showler, J.C. Johnston, M. Sampson, and D. Moher, unpublished data, 2002).

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**KEY WORDS**

hearing loss, hearing screening, hearing impairment, deafness, audiology

**ABBREVIATIONS**

ASL—American Sign Language  
CDC—Centers for Disease Control and Prevention  
D/HH—deaf or hard of hearing  
EHDI—early hearing detection and intervention  
EI—early intervention  
IDEA—Individuals with Disabilities Education Improvement Act  
IFSP—individualized family service plan  
JCIH—Joint Committee on Infant Hearing

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Terminology presented a challenge throughout document development. The committee noted that many of the frequently occurring terms necessary within the supplement may not reflect the most contemporary understanding and/or could convey inaccurate meaning. Rather than add to the lack of clarity or consensus and to avoid introducing new terminology to stakeholders, the committee opted to use currently recognized terms consistently herein and will monitor the emergence and/or development of new descriptors before the next JCIH consensus statement.

For purposes of this supplement:

*Language* refers to all spoken and signed languages.

*Early intervention* (EI), according to part C of the Individuals with Disabilities Education Improvement Act (IDEA) of 2004,<sup>4</sup> is the process of providing services, education, and support to young children who are deemed to have an established condition, those who are evaluated and deemed to have a diagnosed physical or mental condition (with a high probability of resulting in a developmental delay), those who have an existing delay, or those who are at risk of developing a delay or special need that may affect their development or impede their education.<sup>5</sup>

*Communication* is used in lieu of terms such as communication options, methods, opportunities, approaches, etc.

*Deaf or hard of hearing* (D/HH) is intended to be inclusive of all children with congenital and acquired hearing loss, unilateral and bilateral hearing loss, all degrees of hearing loss from minimal to profound, and all types of hearing loss (sensorineural, auditory neuropathy spectrum disorder,<sup>6</sup> permanent conductive, and mixed).

*Core knowledge and skills* is used to describe the expertise needed to provide appropriate EI that will optimize the development and well-being of infants/children and their families. Core knowledge and skills will differ according to the roles of individuals within the EI system (eg, service coordinator or EI provider). This supplement to JCIH 2007 focuses on the practices of EI providers outside of the primary medical care and specialty medical care realms, rather than including the full spectrum of necessary medical, audiologic, and educational interventions. For more information about the recommendations for medical follow-up, primary care surveillance for related medical conditions, and specialty medical care and monitoring, the reader is encouraged to reference the year 2007 position statement of the JCIH<sup>1</sup> as well as any subsequent revision. When an infant is confirmed to be D/HH, the importance of ongoing medical and audiologic management and surveillance both in the medical home and with the hearing health professionals, the otolaryngologist and the audiologist, cannot be overstated. A comprehensive discussion of those services is beyond the scope of this document.

## INTRODUCTION

Since the first universal newborn hearing screening programs were established in the early 1990s, significant progress has occurred in the development and implementation of protocols for screening, audiologic evaluation, fitting of amplification, medical management of children who are D/HH, and support services for families. Despite this progress, provision of the highest quality EI for infants/children who are D/HH and their families remains an urgent priority. The Centers for Disease Control and Prevention (CDC) reported that

over 96.9% of all newborns were screened in 2008.<sup>7</sup> In the United States, there is evidence that earlier identification of children who are D/HH, accompanied by timely and appropriate interventions, can result in language, communication, cognitive, and social-emotional skills that are consistent with children's cognitive abilities and chronological age.<sup>8–10</sup> The ultimate goal of EHDl is to optimize language, social, and literacy development for children who are D/HH.

Although the first EHDl programs in the United States were established more than 20 years ago, most states/territories are not yet able to provide documentation of outcomes resulting from EI services. Lacking such documentation, it is unclear whether state/territory systems are accomplishing the goal of preventing or minimizing communicative delays typically observed in late-identified children who are D/HH. EHDl programs are complex systems requiring a high degree of collaboration at local, state/territory, and national levels among families, birthing hospitals, audiologists, physicians, educational personnel, speech-language pathologists, state health and educational agencies, private service providers, leaders who are D/HH, and support networks. Personnel constraints, financial limitations, and the lack of existing systems have hindered attainment of some of the EHDl goals.<sup>11</sup> This supplement is designed to provide support for the development of accountable and appropriate EI follow-through systems. All goals stated within this document should begin with a baseline measure specific to each state/territory. The goal should be for the program to show annual improvements that lead to 90% attainment of the goal at the end of a 5-year period. An optimal EI service team centers around the family and includes professionals

with pediatric experience. The specific professionals on each team should be individualized on the basis of family needs. This list of professionals may include, but is not limited to, an audiologist, teacher of the D/HH, speech-language pathologist, service coordinator, individuals who are D/HH, and representatives of family-to-family support networks. Depending on the needs of the child, it also could include physical therapists, occupational therapists, psychologists, and educators with expertise in deaf/blind, developmental delay, and/or emotional/behavioral issues.

## BEST PRACTICE GUIDELINES

This best practice document for the implementation of EI services (habilitative, rehabilitative, or educational) is intended to assist the state/territory EHDl systems in optimizing the development and well-being of infants/children and their families. Another goal of this document is to facilitate the development of systems that are capable of continuously evaluating and improving the quality of care for infants/children who are D/HH and their families. Finally, this document outlines best practices to promote quality assurance of EI programs for children from birth to age 3 years and their families.

### **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 state-wide 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 7.<sup>9,17,18</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.<sup>5</sup> 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.

#### *Recommendations*

1. 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.
  - Identify the referral process operating within the state/territory. Establish a timely, coordinated system of entry into EI services. Ensure that providers have the core knowledge and skills necessary to optimize the overall development and well-being of children and their families. Identify methods to report and track individual children from audiologic confirmation to

developmental outcomes. These identified methods often involve coordination between part C at the state or local levels and existing systems of EI for children who are D/HH. Delineate clear and agreed upon responsibilities for all participating agencies, including the development of specific timelines and designation of specific positions for communication and reporting responsibilities. Schedule feedback mechanisms minimally on a quarterly basis (eg, the frequency with which participating agencies will report to the state database regarding enrollment into EI). Develop a flowchart for dissemination of information/data.

- Collect, regularly analyze, and report data on compliance with the requirement for timely access to an EI system. Timely access is defined by this document as referral to part C within 2 days of audiologic confirmation and implementation of services within 45 days of referral. To accomplish this goal, first EI contact with the family should occur within a week of referral. This schedule allows for time to complete the mandated developmental assessment and IFSP within the 45-day timeline. Part C regulations established in 2011 provide for referring a child as soon as possible, but in no case more than 7 days, after the child has been identified with deafness/hearing loss.
2. 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.
- Determine which entity will take responsibility for the development

and update of a state/territory family resource manual.

- Monitor the development or adaptation of a family resource manual, available in different languages and diverse formats (eg, written, captioned video/DVD/Web, video blog, or 3-ring binders), with regular annual updates and revisions that include the following: (1) description of all EI programs and providers, (2) identified Web sites related to deafness and hearing loss, (3) national organizations/resources for families, (4) terms and definitions related to deafness/hearing loss, (5) infrastructure of state resources for families, (6) services available through part C, and (7) communication choices, definitions, and factors to consider.
- Develop a mechanism that ensures that the information contained in the family resource manual provides parents/families with unbiased and accurate information through review by the state/territory EHDI committee or other designated body (eg, parent organization, professional committee). Implement an ongoing quality assurance mechanism (including evaluation) related to the family resource manual.
- Implement a mechanism of dissemination that ensures that all families with newly identified children who are D/HH receive the family resource manual and that the information is reviewed with the family and explained by the service coordinator or EI provider in a timely manner. Family-to-family support (discussed below in goal 9) is an effective mechanism for dissemination of information.<sup>21</sup> Ask families of newly identified infants/

children who are D/HH annually whether they received the family resource manual and if a service coordinator or EI provider reviewed the information with them.

## **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>

### Recommendations

1. Develop or adapt qualifications for service coordinators who contact families after confirmation that their

child is D/HH. Collaborate with part C in a manner that includes the expertise of the state EHDI team or an EHDI task force and EI specialists with expertise in supporting children who are D/HH. These state/territory guidelines should identify the professional qualifications (educational and experiential background) of service coordinators for children who are D/HH and their families.

2. 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. Implement strategies to identify current skills of service coordinators and gaps in their knowledge and skills related to serving families with children who are D/HH. Establish and implement professional development programs that include training in dissemination of information without bias. Provide resources and other supports to assist service coordinators in the acquisition of core knowledge and skills needed to promote successful outcomes for the children and their families.
3. 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.

### **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. Niemeyer, 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).

#### *Recommendations*

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.
2. Ensure that stakeholders participate in the adoption and implementation of these guidelines. Stakeholder categories will include, at minimum, the state EHDI 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.
3. Provide the resources needed for professionals to obtain the core knowledge and skills to serve chil-

dren who are D/HH from birth to age 3 and their families.

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).
5. Identify the number and percentage of EI providers who do not meet the qualifications required but participate in professional development activities specific to EI services and children who are D/HH each year.
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.

#### **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,

\*Similarly, for families who choose cued speech or a manual code of English, professionals should be fluent models of those systems and skilled in enhancing both auditory and visual communication.

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>

### Recommendations

1. Ensure that families have complete and accurate information about ASL.
2. 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. Partners may include EHDI systems, EI professionals with skills in teaching families with infants/toddlers who are D/HH, and individuals who are D/HH with fluent/native ASL skills and experience in teaching families/parents of infants. Agencies that can support development of a statewide system may include schools for the deaf, local education agencies, state coordinators of services for students who are D/HH, the Registry of Interpreters for the Deaf, the ASL Teachers Association, the American Society for Deaf Children, the State Association of the Deaf, the National Association of the Deaf, and the Diagnostic Center at Boys Town National Research Hospital for use and implementation of the Educational Interpreter Performance Assessment.<sup>43</sup>

3. Establish a representative committee that develops guidelines related to the qualifications of sign language instructors. Committees should include specialists in EI strategies for parent/family education and individuals who are D/HH with fluent/native skills and experience in teaching families/parents of infants.
4. 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.
5. 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.
6. Establish and conduct training for ASL instructors that includes strategies and techniques for teaching

sign language to families of infants and toddlers.

7. Establish a quality assurance program for ASL instructors of parents/families. The program should (1) assess their fluency in and knowledge of ASL (existing models for such assessment include the ASL Teachers Association, the Registry of Interpreters for the Deaf, and the ASL Proficiency Interview) and (2) determine their ability to tailor the instruction so that families are prepared to communicate with infants and very young children.
8. 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.
9. Ensure that ASL instructors can accept, without judgment, a family's use of their sign language skills with or without spoken language.

### 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.

#### *Recommendations*

1. Ensure that families have complete and accurate information about listening and spoken language development.
2. 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.
3. Establish qualifications of EI service providers with the core knowledge and skills to develop listening and spoken language (Appendix 2).<sup>48</sup>
4. 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.
5. 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.
6. Establish and conduct training for EI providers to increase their skills

in providing listening and spoken language development.

7. Establish an evaluation of the skills and knowledge of EI providers in their delivery services for listening and spoken language.
8. 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.
9. 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.

#### **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.

### *Recommendations*

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.
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).
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.
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.

### **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.<sup>10,17,50</sup>

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.<sup>51,52</sup>

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.<sup>53–55</sup> 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.

### *Recommendations*

1. 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.
2. 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).
3. 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. Steps should include the following:

- Identify the number of EI providers capable of providing EI services directly in a language other than English.
  - Identify the number of families receiving services that include regular and trained interpreters (knowledgeable about the parent-infant curriculum).
  - Develop materials that are available in the home language or languages of the child or that can be adapted (not just translated from one language to another) to the particular culture and language of the family.
4. 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.
  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.

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 (see [www.sci.sdsu.edu/cdi/adaptations\\_ol.htm](http://www.sci.sdsu.edu/cdi/adaptations_ol.htm) for the MacArthur-Bates Communicative Development Inventories in other languages).

**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.

### *Recommendations*

1. 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 in the following areas:

- language and social-emotional development commensurate with or within 1 SD of their chronological age or cognitive development;
- auditory, listening, vocal, and speech development leading to intelligible and age-appropriate spoken language, if chosen by the family;
- signing, both expressivity and receptivity, leading to appropriate language development, if chosen by the family;
- fine and gross motor development, visual and auditory perception, and measures of adaptive behavior;
- analysis of developmental growth over time: (1) development over time can only be analyzed if the child is assessed with at least some instruments that can be repeated throughout the target age range; (2) if the child's progress in the above domains does not meet expectations, or if critical variables have changed over the course of the time of monitoring, appropriate adaptations to EI services should be made;
- analysis of the quality of the system using progress monitoring: (1) progress monitoring should also be used to assess the quality of the system; (2) states and territories should develop guidelines for determining whether the quality, frequency, and intensity of service is sufficient for adequate progress for an individual child on the basis of his or her progress monitoring.

2. 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 used to improve the skills of the providers and the characteristics of intervention.

3. Develop a collaborative sharing network capable of collecting developmental data for progress monitoring at regular intervals including data reporting to the EHDI database.

### **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.

#### *Recommendations for Monitoring*

1. 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.
2. 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.
3. 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.
4. 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).
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.

6. Develop and disseminate information about the use of amplification for children with hearing loss prepared by consulting audiologists with expertise with infants/children.
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.
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.
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.<sup>70–72</sup>
10. Surveillance should include parent/family counseling and evaluation by a speech-language pathologist to monitor progress in speech and language acquisition.
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.<sup>65</sup>

12. Provide educational information to parents/family covering the following topics:

- impact of hearing loss on the daily life of the child including communication challenges in noisy environments, the difficulty of incidental learning, and the possibility of language/communication delays;
- importance of hearing protection;
- impact of chronic otitis media on residual hearing, and the importance of audiologic and otologic monitoring of hearing status every 3 to 6 months;
- importance of monitoring the communication and social-emotional development of the child;
- availability of EI services (to prevent delay instead of habilitation after delay is identified);
- pros and cons of all amplification options including cochlear implants;
- language options including visual and spoken languages, benefits of multisensory input of language, and the need for ongoing comprehensive evaluation of communication;
- possibility of progression or fluctuation of hearing loss and importance of surveillance by audiology and the medical home;
- importance of medical, genetic, ophthalmologic, and cardiac (EKG) evaluations on children with any type and degree of hearing loss;
- importance of reassessment of treatment/intervention plans

regularly to consider progress in language and communication acquisition, changes in hearing status, changes in amplification choices, and/or changes in communication modes/methods.

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.

### **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.

#### *Recommendations*

1. 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.
2. Report the number of professional family positions (ie, compensated rather than volunteer) and demonstrate how parents and families are involved in recruitment processes.
3. 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.

### **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 responsibility.<sup>75</sup>

#### *Recommendations*

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.

2. Provide the necessary training for families/parents who participate in family-to-family support sessions and activities.
3. Identify collaborative channels to create sustainable and compensated family-to-family support services.
4. Report the number and percentage of families who have had access to appropriate family-to-family supports.

#### **Goal 10: Individuals Who Are D/HH Will Be Active Participants in the Development and Implementation of EHDl Systems at the National, State/Territory, and Local Levels; Their Participation Will Be an Expected and Integral Component of the EHDl 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 EHDl 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 EHDl 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 EHDl systems, it is critical to include D/HH adults in these systems.

Currently, few EHDl 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 EHDl directors, EHDl 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, EHDl systems should partner with national, state, and local organizations that support D/HH persons.

#### *Recommendations*

1. Develop or revise policies and legislation related to EHDl 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 EHDl 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).
2. 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.
3. Report the number of professional positions (eg, compensated and volunteer) filled by individuals who are D/HH at all levels of the EHDl system.

## **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

<sup>†</sup>Although the writers are aware of other states involving deaf community members in similar ways, it is not clear if they are integrated in a formal way in EI and EHDI systems. For this reason, the Colorado program is described.

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>

### *Recommendations*

1. 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 who will

- collaboratively identify potential funding mechanisms for sustainable support services to families from individuals who are D/HH;
- develop and implement guidelines that address providing families with access to D/HH individuals who can provide family support (these guidelines should outline the background and training necessary for support personnel/role models who are themselves D/HH to interact with families of infants/children newly identified as D/HH; these systems should guarantee that families have access to the services regardless of audiologic status (hearing levels or type) and the geographic location of the family);
- develop a leadership training protocol/curriculum for role models and provide leadership training for identified role models;
- develop and implement a mentoring and monitoring system for role models.

2. 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).

## **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).

### *Recommendations*

1. 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. Having developed, approved, and implemented standards for the knowledge and skills needed by providers of EI services to families and children who are D/HH (see Appendix 1) is necessary. Similarly, mechanisms to measure the application of these skills in intervention are required. The most effective means of monitoring the fidelity of intervention is through direct observation and ongoing mentorship.
2. 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.
3. Monitor the fidelity of intervention through direct observation by a highly qualified, experienced EI provider/supervisor. A program of mentorship should be developed with an expert through consultation with individual EI providers. Tele-education/health technology can be used for this purpose. Laptop computers with voice and video communication technology (eg, distance technology) can also provide expert observation and real-time mentoring.
4. Provide mentorship through input on lesson goals and planning.
5. Encourage and support professional development of EI providers.
6. Conduct self-assessments of EI providers to identify their perceptions of strengths and weaknesses related to the guidelines

established in goal 3 (see Appendixes 2 and 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.

7. Measure the progress of EI providers on their knowledge and skills at regular intervals.<sup>86</sup> Refer to Gresham et al<sup>80</sup> for information about how to monitor the quality of interventions.
8. 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.<sup>87</sup>

### **GUIDELINES AND BENCHMARKS**

We recommend collecting data on each of the following recommended guidelines. Our benchmark for all of these is  $\geq 90\%$  of the children/families in each state/territory.

1. All state/territories will have a coordinated system of access to EI services. The system provides timely access to EI professionals who have the knowledge and skills necessary for promoting successful developmental outcomes for children who are D/HH and the capability of tracking individual children from confirmation to developmental outcomes in EI services.
  - Children/families are referred to EI services within 48 hours of confirmation that a child is D/HH.
  - IFSPs are completed within 45 days of referral from confirmation that the child is D/HH.



- All states/territories indicate that they have an annually updated resource manual that is made available and disseminated to all families with newly identified infants/children who are D/HH. States/territories regularly evaluate the comprehensiveness and quality of the information provided in the resource manual.
2. Children/families have timely access to service coordinators who have the core knowledge and skills to fulfill the legal requirements of part C (helping families obtain services, coordinating services, facilitating the timely delivery of services, and continuously seeking appropriate services) and the requisite knowledge and skills unique to working with children, from birth to 3 years of age, who are D/HH and their families.
  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 their development and well-being.
    - Each state and territory has a statement of professional qualifications for providers within 2 years of the publication of this document.
    - All providers meet the stated professional qualifications.
    - States and territories have a statement of the systematic professional development program for EI professionals working with families who have infants/children who are D/HH within 5 years of the publication of this document.
  4. Three areas have been identified as needing specialized skills in addition to the general knowledge and skills required by providers.
    - *Listening and spoken language.* States and territories will adopt a mechanism for ensuring that the professionals providing listening and spoken language services have the knowledge and skills that will facilitate the development of these skills for families who choose these objectives.
    - *Sign language instructors.* States and territories will report the percentage of families and children who are able to access ASL learning opportunities from a skilled, fluent ASL user. All families who chose ASL will have access to trained and skilled ASL instructors who use effective ASL learning programs for families with young children who are D/HH. Families who elect to use sign systems or cued speech also have access to users with fluency.
    - *Other specialized methods.* States and territories will develop a mechanism that ensures intervention providers have the knowledge and skills to teach integrated systems of visual communication and listening/spoken language.
  5. States report that they have developed a system ensuring family participation in the development and implementation of EHDl policies and procedures.
    - All families report that they have access to ongoing family-to-family support.
  6. States report that they have developed and implemented a system ensuring participation of individuals who are D/HH with relevant skills and knowledge in the development and implementation of EHDl policies and procedures.
    - All families report that they have access to professionals/individuals in a variety of different roles who are themselves D/HH.
  7. States/territories develop fidelity monitoring systems and set the goal to begin implementation within 5 years from the publication of this document.
    - Intervention services for families and children who are D/HH are monitored for fidelity of implementation.
  8. Children who are D/HH have their development monitored annually, allowing the state to determine progress toward meeting the developmental outcome goals of EHDl.
  9. States/territories have a system for determining whether EI professionals working with children who are D/HH with additional disabilities have the skills and knowledge necessary to promote successful or optimal/appropriate developmental outcomes for these children and their families. Professionals will receive ongoing in-service education on developmental disabilities (eg, motor, vision, autism, and cognition) and have access to specialists/team members who are qualified to address the specialty areas needed by the child. IFSPs and individualized education programs include the interdisciplinary services necessary to address the broad spectrum of needs presented by children who are D/HH and have additional disabilities.
  10. States/territories will be able to report the number and percentage of families who have children who are D/HH in nonnative English-speaking

homes and identify the home language or languages.

11. States and territories have developed protocols of care for families who do not speak English and/or are culturally diverse, as well as a data management system for monitoring, with a goal of implementation within 5 years of the publication of this document.

## CONCLUDING REMARKS

In conclusion, this best practice statement has advocated for the implementation of coordinated statewide systems with the expertise to provide individualized, high-fidelity EI programs for children who are D/HH and their families. Consistent monitoring of child and family outcomes is an essential step toward ensuring optimal outcomes for the majority of children. There is a great need to strengthen the evidence base supporting specific EI approaches. The establishment of practice standards, implementation of developmentally appropriate protocols for monitoring of outcomes, and commitment to research collaborations are critical steps toward this goal.

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## APPENDIX 1: KNOWLEDGE AND SKILLS OF EI PROVIDERS FOR CHILDREN WHO ARE D/HH AND THEIR FAMILIES

This appendix includes a listing of broad competencies (knowledge and skills) related to the provision of early development services for children who are D/HH and their families. These competencies, compiled from 8 different best practice and position statement documents,<sup>1,32,88–95</sup> are the core competencies recommended for early development providers. The compilation of these core competencies recognizes that early development providers come from diverse professions (eg, audiology, early childhood special education, educators of the D/HH, and speech-language pathology). Although organized into sections by content area, the competencies are intended to be considered as an entire set of practices needed to work with this group of children and families. For example, specific knowledge and skills having to do with cultural competency are incorporated throughout various sections in the document. Note: The Appendix 1A–I tables were developed/compiled by A. Stredler-Brown, M. Sass-Lehrer, K. Clark, and M.P. Moeller.

## APPENDIX 2: EXAMPLE OF FIDELITY OF INTERVENTION MONITORING

### Listening and Language Self-Checklist for Colorado Home Intervention Program (CHIP) Facilitators (Developed By Nanette Thompson) Auditory Skill Development

- ✓ Did I do a version of the Ling 6+ Sound Test? Did I reemphasize the importance of consistency of use of hearing aids/implants throughout all waking hours? Did I do a listening check of amplification?

## Appendix 1A Family-Centered Practice: Family-Professional Partnerships, Decision Making, and Family Support

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
1. Recognize the expertise and major impact of families on children's growth and development	1, 32, 88, 90, 93
2. Understand family systems and family dynamics	32, 88, 90, 93
3. Establish respectful reciprocal relationships with families	32, 88, 90, 93
4. Demonstrate appropriate and effective listening strategies with families and others	32, 88, 90, 93
5. Facilitate families' identification of concerns, priorities, and resources	32, 88, 90, 93
6. Implement strategies to promote infant-caregiver relationships and interactions	32, 88, 89, 90, 93
7. Promote and enlist help from family-to-family support networks	1, 32, 88–93
8. Support family health and emotional well-being	32, 88, 90, 93
9. Identify risks for abuse/neglect situations	32, 88, 90, 93
10. Provide support and recognize signs indicating the need to refer for counseling/therapy or other emotional support from specialists	32, 88, 90, 93
11. Encourage family skills for collaboration with the EI team	1, 32, 88, 89, 91, 93
12. Promote family involvement in all aspects of intervention	1, 32, 88, 89, 91, 93
13. Promote informed decision making through provision of accurate and comprehensible information, resources, and support	1, 32, 93
14. Implement strategies for guiding and supporting families' decisions regarding communication approaches/opportunities	1, 32, 88–93
15. Encourage family advocacy skills	1, 32, 88, 89, 91, 93
16. Monitor family satisfaction with intervention services	1, 32

## Appendix 1B Socially, Culturally, and Linguistically Responsive Practices Including D/HH Cultures and Communities: Sensitivity to and Respect for an Individual Family's Characteristics

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
1. Understand the diversity of families, languages, cultures, communities	1, 32, 88–93
2. Understand the influence of family, culture, and environment on infant development	1, 32, 88, 90–93
3. Understand the implications of socioeconomic and cultural differences in child rearing	1, 32, 88, 90–93
4. Demonstrate sensitivity to cultural, religious, ethnic, disability, gender, socioeconomic, linguistic, and geographic influences on children and families	32, 88, 93
5. Demonstrate understanding of and respect for deaf culture and D/HH communities	32, 91–93
6. Understand the role and resources of the deaf community, sign language interpreters, and cultural brokers	1, 32, 89, 92, 93
7. Appreciate the roles and access the resources of interpreters and cultural brokers when working with non-English-speaking families	32, 90, 91
8. Promote family's understanding and appreciation of "being deaf or hard of hearing"	None
9. Understand the role and include resources of D/HH adults to promote language and social development and use of technologies (auditory and visual)	1, 32, 89, 91, 92
10. Appreciate and respect cultural perspectives on selection and use of technology	32
11. Implement culturally sensitive approaches	1, 32, 88–93

## Appendix 1C Language Acquisition and Communication Development: Typical Development, Communication Approaches Available to Children With Hearing Loss, and Impact of Hearing Loss on Access to Communication

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
1. Understand developmental sequences across developmental domains and their complex interactions with communication	1, 32, 88, 90, 93
2. Understand the influence of variables such as age of identification/intervention on language (English and other spoken languages, ASL) and speech acquisition	32, 88, 93
3. Understand the effects of multiple language exposure on children's development (ie, bilingualism in spoken languages and in ASL), drawing upon current theories of bilingualism	32, 88, 90, 93
4. Understand the impact of hearing loss on communication, language, and speech	1, 32, 88
5. Promote the important role of caregivers in development of communication skills through caregiver-child interaction	1, 32, 88–93
6. Understand typical development sequences in auditory and visual perception	1, 32, 88–90, 93
7. Understand the array of communication approaches (eg, ASL, bilingual-bicultural, auditory/oral, auditory/verbal, cued speech, and simultaneous communication) and resources for observing and demonstrating them	1, 32, 88–90, 93
8. Understand augmentative communication approaches and circumstances in which they should be considered	90, 93
9. Understand the importance of involving D/HH adults in the promotion of children's language and social development	1, 32, 89, 91, 92

**Appendix 1C** Continued

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
10. Provide families and children with access to skilled and experienced professionals to facilitate language development using language and communication modalities selected by family and appropriate for the child	1, 32, 90
11. Coach families in the use of strategies that promote a language-rich learning environment to facilitate language, thought, and early literacy	1, 32, 88–93
12. Prepare families to be able to explain (or understand) the relationships among communication, language, and speech	1, 88, 93
13. Assess prelinguistic and early linguistic communication stages	1, 32, 88, 93
14. Understand communication and language assessment outcomes with reference to typical developmental sequences and stages of spoken language development	1, 32, 88–92
15. Interpret outcomes with reference to typical developmental sequences and stages of ASL for families using this approach	1, 32, 89, 91, 92
16. Promote development of phonology, morphology, syntax, semantics, and pragmatics of spoken language and/or ASL	88
17. Implement strategies to promote auditory learning in children who are D/HH	1, 32, 88–90, 93
18. Implement strategies to promote visual language learning in children who are D/HH	
19. Embed goals within daily routines and integrate communication in a variety of social, linguistic, and cognitive/academic contexts	1, 32, 88–90, 93
20. Implement strategies that promote access to language using combined or multiple modalities	32, 88, 89, 91, 92
21. Implement current practices for promoting auditory development for children with cochlear implants	1, 88
22. Implement evidence-based communication practices with young children to facilitate child learning within developmentally appropriate daily activities	88, 90, 93
23. Monitor language development outcomes to guide intervention and promote age-appropriate abilities to the degree possible	32, 88–91

**Appendix 1D** Factors Influencing Infant and Toddler Development

Providers have the knowledge and skills to	Best Practice Documents (Ref No.)
1. Differentiate the characteristics and stages of typical/atypical development	1, 32, 88–91
2. Appreciate the range of individual differences in development and factors that influence them	1, 32, 88–93
3. Recognize the effects of prenatal care, prematurity, health, and other biological conditions on development	90, 93
4. Be aware of the health needs of young children and collaborate with the medical community to address them	93
5. Understand contemporary infant development theories including research on brain development	32, 88, 89, 93
6. Demonstrate sensitivity to infant states/cues and understand how responses contribute to infant development in child rearing	32, 93
7. Understand bonding/attachment theories and implications for development	93
8. Monitor stages of cognitive development and recognize the impact of cognitive delays on learning	32, 88, 89
9. Recognize the impact of multiple disabilities on development and understand the interdependence of developmental domains	88–90, 93
10. Understand auditory, visual, and cross-modal perception and processing in relation to development	32, 88, 91–93
11. Recognize the role of play and daily routines in development	32, 88, 90, 93
12. Locate current evidence and resources related to contemporary studies of infant development	32, 88, 89, 93
13. Facilitate infant/toddler engagement	88, 90
14. Develop and implement age-appropriate interventions supportive of development in all domains and reflective of individuals' interests	32, 88–90, 93

**Appendix 1E** Screening, Evaluation, and Assessment: Interpretation of Hearing Screening and Audiologic Diagnostic Information, Ongoing Developmental Assessment, and Use of Developmental Assessment Tools to Monitor Progress

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
1. Distinguish between screening, observation, evaluation, and assessment	90, 93
2. Understand and facilitate referral processes (from screening, evaluation, and referral for services)	32, 93
3. Understand implications of universal newborn hearing screening for families and early intervention services	1, 90, 93
4. Understand newborn hearing screening protocols, including instrumentation; appropriately interpret screening results	1, 88
5. Understand pediatric audiologic procedures, including screening, evaluation, and interventions and accurately interpret audiologic results	1, 88, 90, 93
6. Promote and provide input to appropriate audiologic and developmental evaluation procedures	32, 88, 93
7. Understand atypical development etiologies and diagnoses and refer for medical-genetic evaluation	1, 32, 88, 90, 93



## Appendix 1E Continued

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
8. Know how to gather information from families that identifies their priorities, concerns, and resources related to their child's development	32, 88, 90
9. Know current cochlear implant candidacy criteria	1, 88
10. Recognize strengths and limitations of standardized instruments and adaptations for a child who is D/HH	90, 93
11. Use assessment tools and strategies that are culturally, linguistically, and developmentally appropriate	32, 90, 93
12. Understand and participate in interdisciplinary, transdisciplinary, and multidisciplinary assessment procedures and processes	90, 93
13. Implement assessment strategies and support family participation and involvement	32, 88, 93
14. Implement principles/processes to appropriately assess the child in natural environments	88, 90, 93
15. Monitor child progress by using appropriate tools and procedures	1, 32, 88–90, 93
16. Convey assessment and evaluation results and recommendations in a manner that is understandable, accessible, culturally sensitive, and confidential	1, 32, 90, 92, 93

## Appendix 1F Technology: Supporting Development by Using Technology to Access Auditory, Visual, and/or Tactile Information

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
1. Recognize the importance of the use of technology to access auditory, visual, and/or tactile information	1, 88–93
2. Recognize benefits and challenges of technology use with infants across multiple settings and activities	32, 88, 90, 93
3. Be knowledgeable about current augmentative communication technologies and their application with infants with multiple special needs	88
4. Identify sources for obtaining assistive technology, information, funding, and support	1, 32, 93
5. Implement strategies to support families' abilities to use and monitor effectiveness of technology	1, 32, 88, 90, 91, 93
6. Promote family skills in monitoring amplification and ensuring device retention and safety	1, 32, 88–90
7. Promote family learning and involvement using household, office, and community technology	32, 88, 93

## Appendix 1G Planning and Implementation of Services: Creating a Lesson Plan, Conducting a Home Visit, Developing the IFSP, and Using Appropriate Curriculums, Methods, and Resources

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
1. Implement best practices related to the process of developing IFSPs and Individual Education Plans	1, 32, 88–90, 93
2. Collaborate with families to develop and implement the IFSPs as working documents	1, 32, 89, 90, 93
3. Plan and implement assessment-based instruction	88, 90
4. Select and systematically implement intervention strategies appropriate to the communication, hearing, speech, language, and emerging literacy needs of the child	88, 90
5. Revise intervention approaches as needed in response to the child and the family	1, 32, 88–90, 93
6. Plan and implement effective parent-child sessions in natural environments	32, 88, 90
7. Plan and implement center-based session (eg, play groups and peer groups) including developing effective lesson plans	32, 88
8. Participate in the planning and implementation of workshops/meetings for families	None

## Appendix 1H Collaboration and Interdisciplinary Models and Practices

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
1. Recognize roles and responsibilities of families and other individuals with expertise in deafness	1, 32, 89, 90, 93
2. Support consultation across disciplines and collaborate with families	1, 32, 88–90, 93
3. Recognize the roles and the importance of service coordination and medical homes	1, 32, 90, 93
4. Promote collaboration with community programs and resources to support families and children	1, 32, 90
5. Recognize intra/interpersonal variables that influence the development of collaborative relationships with parents and professionals	1, 32, 88–90, 93
6. Apply principles and strategies to support family members and professionals	1, 32, 88–90, 93
7. Implement collaborative strategies for communicating, decision making, and resolving conflict	32, 90, 93
8. Provide for a continuum of service delivery models to meet the needs of the individual child and family (eg, direct service, collaborative consultation, playgroup based)	90
9. Assume a leadership roles affecting collaboration, including self-evaluating, mentoring, networking, and advocating for families and organizations	32, 88, 90, 93

**Appendix 11** Professional and Ethical Behavior: Foundations of EI Practice, Legislation, Policies, and Research

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
1. Understand history of deaf education, philosophy of early intervention, and child/family advocacy	88, 91, 92, 93
2. Understand EHDI programs and processes	32, 89, 90
3. Understand IDEA, federal legislation, and federal regulations related to infants/toddlers and their families	1, 32, 89, 90, 93
4. Recognize IDEA's support for program evaluation and system change and the limitations of the law	32, 93
5. Support the rights, responsibilities, and confidentiality of children and their families	1, 32, 89, 91
6. Understand the role of Services Coordination and assist families in linking with this service	32, 90
7. Plan and implement seamless transitions to ensure continuity of services across educational and community placements	1, 32, 88–90, 93
8. Apply principles of evidenced-based practice and be conversant about current research evidence related to early intervention	32, 88–90
9. Adhere to professional ethical standards in working with young children and families	32, 88, 89, 93
10. Take personal responsibility to demonstrate a positive attitude toward infants, toddlers, and families	93
11. Think critically and pursue life-long learning through ongoing professional development	1, 32, 88, 89, 93

✓Did I incorporate music, nursery rhymes, or singing into the session?

✓Did I demonstrate high expectations for auditory skill development in daily routines and natural environments? Did I encourage a variety of listening activities including recorded music or books on tape?

✓Did I provide opportunities to listen in a variety of environments including with varying distances and in quiet and noisy environments?

✓Did I encourage the family to organize the environment to maximize the auditory potential of the child? (Decrease background noise, turn off the TV, close the doors to the laundry room, etc.)

### Language Development

✓Did I use literature in the session or reference activities that encourage early literacy skill development?

✓Did I model expanding the child's spontaneous language and discuss the importance of this strategy with the parent? Did I use the Plus 1 rule of expanding the child's utterance by 1 additional word?

✓Did I reward all attempts at communication?

✓Did I focus on the development of language through listening? Did I

remind the parent to talk to the child throughout daily activities?

### Speech Sound Production

✓Did I expect, encourage, and elicit verbal responses within all activities?

✓Did I use acoustic highlighting to facilitate speech sound production?

✓Did I note any speech errors and understand them to be developmental, phonological, motor-related, or hearing-related in nature?

### Techniques, Strategies, and Communication

✓Did I provide commentary for parents of my session objectives and my observations?

✓Did I demonstrate scaffolding a skill up and down to ensure the child's success and discuss that important process with the parent?

✓Did I provide enough pause time and encourage the parents to do so as well?

✓Did I brainstorm with the parents ways to incorporate these strategies and objectives into their daily routines?

✓Did I follow up with other professionals working with the child?

✓Did I leave the parent feeling empowered and motivated for the upcoming week?

### APPENDIX 3: EXAMPLE OF FIDELITY OF INTERVENTION MONITORING FOR ASL FOR USE BY PARENTS AND PROVIDERS/FACILITATORS WITH CHILDREN AGES BIRTH TO ≥4 YEARS (DEVELOPED BY BETH S. BENEDICT, PHD, JODEE S. GRACE, MA, AND PETRA HORN-MARSH, PHD)<sup>94,95</sup>

#### Visual Skill Development

- Did I monitor the child's progression through developmental stages of ASL? Do I know what behaviors are typically observed at the preverbal stage, single-word stage, 2-word stage, and short-phrase stage in young ASL users? Do I emphasize the importance of consistency of use of ASL by the family throughout the child's waking hours? Do I do a visual<sup>‡</sup> check of natural and

<sup>‡</sup>Visual checks include picking the child up so he/she has a better view of what's "up there" (ie, counter at McDonald's to order food from a cashier), carrying the infant facing forward so that the infant can see what the caregiver is doing and talking about, making sure that the child is positioned so he/she has "the best eye view of the world," and ensuring that the caregiver has a large rearview mirror in the car so that the parent and child can see each other better and thus the caregiver can "communicate" with the infant or child.

structured development opportunities and interactions that foster skill growth?

- Did I model infant-directed sign (“motherese”), utilizing my facial expressions and hand touches on the baby?
- Did I model the use of and support the family in ways to incorporate finger play, nursery rhymes, gestures, body language, or facial expressions into daily routines (active and passive activities)?
- Did I demonstrate high expectations for visual skill development in daily routines and natural environments? Do I encourage a variety of visual activities including DVDs, print books, and storytelling that are interactive?
- Did I provide opportunities for joint engagement, incorporating eye contact, eye gaze, and eye shifting in a variety of environments, at varying distances, and in nondistracting visual environments? Do I know that the child is able to pay attention and is aware of the words being exchanged? Do I support the family in providing ample opportunity for turn-taking to foster skill development?
- Did I encourage the family and other people to organize the environment to maximize visual potential of the child (eg, the room is well-lit, the background is not too graphic, the seating is in appropriate proximity, and there are plenty of meaningful conversational exchanges, appropriate to the child’s developmental level)?
- Did I respond appropriately to the child’s attempts to initiate and express self (eg, do I show that I understand through my ASL and then build on to the child’s communica-

tive attempt)? Do I model these skills for families and promote their use?

### Language Development

- Did I use children’s literature and other strategies to encourage early literacy skill development?
- Did I model expanding the child’s spontaneous language and discuss the importance of this strategy with others involved? Do I use a language development checklist or scale to ensure that the child is making language gains within age-appropriate intervals? Do I expose the child to other language models (adults and peers) so that the child can acquire a variety of developmental styles?
- Did I motivate, encourage, and reinforce all attempts at communication, supporting semantic, grammatical, social-pragmatic, and verbal reasoning skills?
- Did I recognize the effects of the child’s learning style and temperament on language development so that individual needs are consistently nurtured and supported?
- Did I expect ASL acquisition to follow the developmental milestones similar to those of spoken language?
- Did I focus on monitoring the child’s development of language through watching/observing/attending and measuring outcomes? Do I recognize that the child has initiated, maintained, and responded to conversation, including appropriately answering basic questions?
- Did I coach the other parents/providers to communicate with the child in ASL throughout daily activities and routines, including incidental conversation, side

conversations, and background noises?

### ASL Production

- Did I expect, encourage, and elicit signed responses from the child within all activities?
- Did I support the family in developing similar expectations for the child’s ASL production?
- Did I incorporate hand-shape, location, movement, palm orientation, facial expression (non manual markers on eyes, face, and head), and body posture to facilitate ASL production?
- Did I note any ASL grammatical errors made by the child and consider whether they are developmental, cognitive, motor, or visual in nature?

### Techniques, Strategies, and Communication

- Did I suggest and encourage the family to use Videophone, Skype, iChat, ooVoo, or other visual technology for ongoing communication in ASL?
- Did I provide commentary for parents and/or providers/facilitators on the language goals and observations of the child’s emerging skills and ongoing needs?
- Did I demonstrate ways to scaffold<sup>§</sup> a child’s emerging skills to ensure the child’s success? Do I support the family in developing methods for scaffolding the child’s development (eg, assisting the child in making the appropriate hand-shape, beginning with the 6 basic hand-shapes [B, A, C, 0, 5, 1], then increasing to more complex hand-shapes [claw-5, claw-3]; supporting the caregiver in knowing that the child learning ASL typically has

<sup>§</sup>Did I foster skill growth to the next level using visual aids, manipulative, concrete examples, and situations? For example, asking a child “which” question occurs before the next questioning level, such as who, what, or where?

a vocabulary of  $x$  number of signs by age 2, etc)?

- Did I provide enough pause time and encourage the parents and/or providers/facilitators to do so as well? Do I coach them on “give and take” strategies so that the child can develop independent critical thinking skills?

- Did I brainstorm with the parents and/or providers/facilitators on ways to incorporate these strategies and objectives into their daily routines?
- Did I collaborate with other providers/facilitators (eg, occupational therapist, physical therapist, speech language pathologist) serv-

ing the child and family members, sharing input, and providing ongoing development as well as opportunities to increase their ASL skills?

- Did I leave the parent and/or providers/facilitators feeling empowered and motivated to support the child's ongoing ASL development?

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