

JCIH State Self-Assessment Work Group



Final Report

2/1/17

To the Reader:

The Final Report of Illinois’ JCIH State Self-Assessment Work Group recommends actions to improve the quality of care provided to hearing-impaired infants and toddlers enrolled in Illinois’ Early Intervention (EI) Program.

The Work Group was led by the three state agencies involved in serving young children with hearing loss: the Illinois Department of Human Services, the Illinois Department of Public Health, and the University of Illinois at Chicago Division of Specialized Care for Children. The full Work Group included 30 service providers and families of children with hearing loss. It held three day-long meetings in the summer of 2016. A roster of participants is presented in this report.

In 2007, the Joint Committee on Infant Hearing (JCIH) provided comprehensive guidelines to develop and maintain strong EI systems to meet the needs of children who are deaf or hard-of-hearing. A supplement was published in 2013. The guidelines were developed by teams of professionals with expertise in Early Intervention services for children who are deaf or hard-of-hearing and their families. The guidelines were based on literature searches, existing systematic reviews, and recent professional consensus statements.

Recognizing that guidelines for best practices in early intervention existed and that gaps in service delivery were present, an Early Hearing Detection and Intervention System Self-Assessment Tool was designed to help the leaders of state EI systems evaluate their programs and initiate quality improvement. The JCIH 2014 Early Detection and Intervention System Self-Assessment Tool was developed by a team of EI specialists, state newborn hearing program representatives, parent representatives, quality improvement advisors, and researchers from North Carolina, Minnesota, Maine, and Georgia. The tool’s purpose is to assess a state’s full EHDI system rather than evaluate a specific program, agency, or entity.

Illinois’ work group used this tool to assess the current status of services available to children with hearing loss in the state’s EI program. The group identified four high-priority goals and formulated recommendations for improving services. The four goals include:

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.

Goal #2: All children who are D/HH and their families experience timely access to services coordinators who have specialized knowledge and skills related to working with individuals who are D/HH.

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.

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.

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Professionals have provided early intervention services to infants and toddlers with disabilities and their families since Congress established the Program for Infants and Toddlers with Disabilities (Early Intervention or EI) in 1986 as Part C of the Individuals with Disabilities Education Act (IDEA). Part C is a federal grant program that helps states to operate a comprehensive statewide program of early intervention services. According to Part C of IDEA 2004, “(EI) 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 of special need that may affect their development or impede their education.” (1).

Part C services are beneficial for infants and toddlers who are deaf or hard of hearing (D/HH). Research has consistently shown that children who receive EI services before 6 months of age are more likely to have normal language development by the time they start school. (Pipp-Siegel, et al., 2011). On the strength of this evidence, Congress authorized funding to develop state “Early Hearing Detection and Intervention” (EHDI) programs in 2000. Enrollment and participation in EI is an essential link in a chain of events that begins with universal screening for hearing loss at birth. Next, infants who have a positive screening result are referred to a pediatric audiologist for a diagnostic evaluation. Infants with confirmed (diagnosed) hearing loss are then referred to the EI system. State EHDI programs are charged with tracking these infants from birth through EI enrollment to ensure that each child with a hearing loss has the opportunity to benefit from EI services.

Although infants and toddlers with hearing loss and their families had access to services under Part C prior to the initiation of the EHDI program, these children were often identified too late to be enrolled in and benefit from Part C services. Since the initiation of EHDI programs in 2000, “the age of identification of hearing loss has moved from an average of 2 to3 years to an average of 2 to3 months of age (White, et al., 2010).”(2) However, initial screening and diagnosis of hearing loss in an infant or toddler is meaningless without appropriate, individualized, and high-quality intervention. In all of the research documenting positive linguistic, social, and developmental outcomes, the enrollment in appropriate early intervention made the greatest impact on meeting the outcomes parents sought for their children. (3) While state data gathered by the federal Centers for Disease Control and Prevention continues to indicate that initial identification of hearing loss has increased, most states have not been able to document the benefits of timely enrollment and continued participation in appropriate EI services. This lack of evidence makes it unclear whether state systems are accomplishing the goal of preventing or minimizing communication and language delays typically observed in late-identified children who have hearing loss.

Many organizations and experts have made evidence-based recommendations to improve the quality and effectiveness of state EI services for infants and toddlers who are D/HH. These include recommendations from the Joint Committee on Infant Hearing (JCIH 2007; 2013) (Appendix 1); the Joint Committee of American Speech and Hearing Association and the Council on Education of the Deaf (ASHA, CED 2008b); the National Consensus Conference Report (Marge & Marge 2005); (5) and an international panel of experts (Moeller, Carr, Seaver, Stredler-Brown, & Holzinger 2013). (6).

In particular, the 2007 position statement from the Joint Committee on Infant Hearing (JCIH) provided comprehensive guidelines to develop and maintain strong EI systems to meet the needs of children who are D/HH. A supplement was published in 2013. It was written by teams of professionals with expertise in EI programs for children who are D/HH and their families and was based on literature searches, existing systematic reviews, and recent professional consensus statements (Schacter, TJ. Clifford, E. Fitzpatrick, S. Eatmon, M. Morag, A. Showler, J.C. Johnston, M. Sampson, and D. Moher, unpublished 2002) (7-8). This document makes recommendations with benchmarks that states can adopt to improve care and treatment of children with hearing loss in their EI systems.

Recognizing that guidelines for best practices in early intervention existed and that gaps in service delivery were present, an Early Hearing Detection and Intervention System Self-Assessment Tool was designed to help the leaders of state EI systems evaluate their programs and initiate quality improvement. The JCIH 2014 Early Detection and Intervention System Self-Assessment Tool (Appendix 2) was developed by a team of EI specialists, state EHDI representatives, parent representatives, quality improvement advisors, and researchers from North Carolina, Minnesota, Maine, and Georgia. The tool’s purpose is to assess a state’s full EHDI system rather than evaluate a specific program, agency, or entity. “This assessment is best completed by a team of state stakeholders, in partnership with the EHDI community and family leaders.” (9) A self-assessment process allows for a variety of stakeholders to participate, provides an avenue to explore state systems strengths and needs, and guides improvement efforts.

Illinois’ lead agencies for EHDI and EI recognized the need for change. These agencies convened a short-term stakeholder workgroup and used the JCIH 2014 Early Detection and Intervention System Self-Assessment Tool to identify priorities and develop an improvement plan.

**Illinois EHDI:**

Illinois has three state agencies directly involved in EHDI: the University of Illinois at Chicago’s Division of Specialized Care for Children (Illinois’ program for children with special healthcare needs under Title V of the Social Security Act and the grantee for EHDI funds from the federal Health Resources and Services Administration), the Illinois Department of Public Health (Illinois’ Title V lead agency and grantee for EHDI funds from the federal Centers for Disease Control and Prevention), and the Illinois Department of Human Services’ Bureau of Part C Early intervention (Illinois’ grantee for the Part C Early Intervention program). Materials on each agency are available on the following websites:

* Illinois EHDI - [www.illinoissoundbeginnings.org](http://www.illinoissoundbeginnings.org) (10)
* Division of Specialized Care for Children (DSCC) - [www.dscc.uic.edu](http://www.dscc.uic.edu) (11)
* Department of Public Health (IDPH)- [http://dph.illinois.gov](file:///%5C%5Ccaodata%5Cusers_spfld_cao%5Crms%5CEHDI%5CJCIH%20Recommendations%20for%20EI%5CFull%20Report%5CAlex%20Dalton%20-%2081506912), <http://dph.illinois.gov/topics-services/life-stages-populations/newborn-screening/hearing>
* Illinois Early Intervention - <http://www.dhs.state.il.us/page.aspx?item=31889> (12)

DSCC helps families navigate their child’s health care and provides comprehensive care coordination services. DSCC also works with healthcare service providers to improve the operation of Illinois’ EHDI system. The IDPH manages the tracking system and follows up with hospitals, primary care providers, audiologists, and families to ensure that children are screened by 1 month of age, receive a diagnostic evaluation by 3 months of age, and have the opportunity to enroll in EI services by 6 months of age. Illinois’ Early Intervention program aims to assure that the families of children under 3 years of age who either have a diagnosed developmental delay or a substantial risk of significant delays receive resources and support that help them maximize their child’s development, while respecting the diversity of families and communities. The EI program funds 25 community-based organizations to serve as “Child and Family Connections” agencies (CFCs or system entry-points) to develop and implement Individualized Family Service Plans (IFSPs) for each eligible child. Each of these 25 offices hires a program manager, service coordinators, and other staff to serve a designated geographic area. The Bureau of Part C Early Intervention credentials direct service providers (therapists and other specialists) in relevant disciplines and reimburses them on a fee-for-service basis. (Service providers are not employed by the Child and Family Connection offices to avoid conflict of interest.)

**EHDI System Self-Assessment Tool; Getting Started In Illinois:**

A Leadership Team comprised of members from each of the three state agencies and a contracted project facilitator developed a list of stakeholders who were considered to be design-thinkers and problem-solvers. They were invited to participate in a four-month Workgroup process. Materials were sent to each one outlining the scope of the project and asking for three things:

(1) A commitment to participating in three face to face meetings held in July, August, and September 2016;

(2) Completion of the self-assessment tool; and

(3) Participation in webinars to be held in June and July.

Thirty stakeholders accepted the invitation and committed to participate in all of the activities. The Workgroup represented the entire state, with 70 percent of the participants from northern Illinois, 23 percent from central Illinois and 7 percent from southern Illinois. (This generally follows the distribution of the state’s population.) Stakeholders included parent leaders, audiologists, Early Intervention service providers, individuals with hearing loss, and agency staff.

The Illinois EHDI System Self-Assessment Tool was formatted as a survey in Survey Monkey (a web-based survey tool) for ease of administration and analysis. A few items were added to the JCIH tool, (Appendix 3), including the collection of demographic information and two additional ranking measures. Through dialog and discussion, the Leadership Team ranked each of the 12 JCIH goals and subgoals from their agency’s perspective. This process allowed discussion and opportunities for all three agencies involved with EHDI to share current activities and any upcoming quality improvement projects. Stakeholders also completed the self-assessment tool through Survey Monkey and ranked the goals and subgoals in three ways. They ranked the 12 JCIH goals first by importance and second by feasibility. They were asked to rank each goal as “high importance” (ranked 1-4), “mid-level importance” (ranked 5-8) or “lower-level importance” (ranked 9-12). Thinking specifically about Illinois, each stakeholder was then asked to rank the 12 JCIH goals by feasibility, assessing the likelihood of seeing actions or recommendations through to completion given limited resources. Each goal was ranked as “highly feasible” (most easily accomplished), “mid-level,” or “least feasible (most difficult to accomplish). Thirdly, as the EHDI System Self-Assessment Tool specified, the Workgroup participants rated the state’s current status on each goal and subgoal using the established scale of “nothing in place” (1), “just beginning” (2), “making good progress” (3), “established practice” (4), or “cannot assess” (5).

These data were then tabulated and distributed to the Workgroup members for discussion at each of the face-to-face meetings.

An introductory webinar was held to familiarize each participant with the state assessment tool and provide direction for survey completion. The Workgroup facilitator hosted the webinar. A survey completion deadline was set, allowing time for data to be organized prior to the first face-to- face meeting. The facilitator was responsible for organizing the data, identifying trends relevant for the group to discuss, and presenting the data by goal and subgoal so the group could reach a consensus during the meetings.

The Workgroup met for three five-hour days over a four-month period. Specific goals were set for each meeting. The goal for the first meeting was to reach consensus on the JCIH goals that would be considered high-priority goals for Illinois. The second meeting’s goal was to reach consensus on subgoals after a review of the data from the identified priorities. The goal set for the final meeting was to generate action steps under each subgoal and to propose measurements for quality improvement activities in the prioritized goal areas. The Workgroup shared these recommendations with the three Illinois agencies to determine the timeline for implementation and follow-up actions.

Following the first meeting, materials were gathered and shared electronically with Workgroup members to better familiarize everyone with policies and procedures already in place within the Early Intervention system (Appendix 4). Summary notes were distributed after each meeting and some members were given tasks to complete prior to the next face- to- face meeting.

**EHDI System Self-Assessment Tool; Illinois Data Results:**

1. **Identified Goal Priorities**

While recognizing that each of the 12 JCIH-recommended goals were important, stakeholders realized that it would not be feasible to develop action plans to meet all 12 goals. By analyzing the high and low scores obtained from the Leadership Team and the stakeholders, the Illinois Workgroup data showed goals that ranked highest and lowest in importance and in feasibility. During the facilitated large group discussion at the first face-to-face meeting, the group identified four goals as priorities to address moving forward. All ranking data in all the 12 goals were saved for future use.

 High Importance: Goals High Feasibility: Goals

 1,2,3,7 1,2,3,7

 1,2,3,7

1. **Identified Subgoal Priorities**

While subgoal data was collected on all of the 12 goals, the Workgroup focused their discussion on the subgoals associated with the priority goals. By using the numeric scores provided by the rankings of Nothing in Place, Just Beginning, Making Good Progress, and Established Practice, stakeholders were able to see how state systems and existing policies interfaced. Small group and large group discussions were used to provide each participant a chance to listen and share their reasoning for how they ranked and rated each of the subgoals. It also allowed the group to recognize some of the accomplishments that are working successfully for families in Illinois that deserve to be highlighted and maintained. The focus of these discussions centered on prioritizing subgoal recommendations by importance. Following consensus of subgoal importance, action plans and needs assessments were developed; they are presented later in this document.

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|  **Illinois JCIH Goal Priority** |  **Illinois JCIH Subgoal Priorities** |
|  Goal 1 | 1.1, 1.2 |
|  Goal 2 | 2.2 |
|  Goal 3 | 3.1a, 3.1b, 3.3, 3.3a, 3.4, 3.4a, 3.6 |
|  Goal 7 | 7.1, 7.6, 7.9 |

**Illinois identified need:**

**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.*

Part C of the IDEA allows eligible infants and toddlers to receive EI services from birth to age 3 years. These services are provided according to an Individualized Family Service Plan (IFSP). Since enrollment into the EI program is voluntary, coordination between local CFCs and state EHDI programs is critical so that all families receive information that will help them achieve desired outcomes for their children. The EI program averaged 20,689 active IFSPs during each month of state fiscal year 2016.[[1]](#footnote-1) This number includes children with hearing loss and shows the robust involvement across the state. The Bureau of Part C Early Intervention and the state public health department’s EHDI program began collaborating to monitor the number of children referred for services following diagnosis of hearing loss who were subsequently enrolled in EI services. According to data for calendar year 2015 from the IDPH tracking system, 252 children with confirmed hearing loss were referred to EI. Of these, 32 were unknown to EI through a lack of follow-up by an audiologist, by the CFC not acting on the referral, or because the family had “dropped out” of the follow-up system. An additional 35 children were referred but never received an IFSP because the parent did not respond or chose not to participate in EI. This Workgroup reviewed the process from referral to EI entry and became more familiar with barriers preventing smooth referral practices, entry and tracking outcomes in to EI.

Illinois Early Intervention has established medical eligibility criteria for a child with hearing loss. They are: “Hearing loss of 30dB or greater at any two of the following frequencies: 500, 1000, 2000, 4000 and 8000 Hz; or hearing loss of 35 dB or greater at any one of the frequencies: 500, 1000 and 2000 Hz; involving one or both ears“(13).

**Identified Subgoals under Goal #1 with Recommended Action Plans:**

* 1. *Share a baseline analysis of EHDI 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.*

While hospital referral rates[[2]](#footnote-2) have decreased appropriately with the implementation of otoacoustic emission (OAE) technology, and the rate of loss-to-follow-up following hospital discharge has dropped from 81 percent to 46 percent, attention in this area continues to be a high priority.

The recommended action steps are:

A. Develop and implement tracking system utilizing Initial Developmental Therapists/Hearing (DT/H) Evaluators credentialed in Early Intervention for start date of all children who had Aural Rehabilitation evaluation and were enrolled in EI.

B. Utilizing Early Intervention providers and Designated Service Coordinators serving the D/HH population, develop and implement tracking system for six-month IFSP meeting and annual IFSP meeting to track continued enrollment or dismissed from Early Intervention.

-- Utilize ongoing DT/H, Speech Language Pathologists and Service Coordinators for data collection and reporting.

C. Confirm and post EI eligibility for each agency and incorporate into training materials.

D. Confirm Pediatric Audiologists listed on EHDI Pals; increase visibility of this site and incorporate into training materials.

E. Develop and implement tool to increase communication between referring audiologists and CFC staff, specifically Designated Service Coordinators.

F. Investigate use of universal referral form for audiologists across the state.

G. Increase average number of children with hearing loss enrolled into EI (currently at 68 percent)

1.2 *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.*

The recommended action steps are:

A. Use Sound Beginnings to house resources for Service Coordinators, Initial Evaluators, and other service providers.

B. Develop a checklist for Initial Evaluators to include with the report and participation at initial IFSP meetings with resources supporting parents and families.

- Survey existing initial evaluators for materials currently being shared.

- Develop learning community for the initial evaluators to be involved in the development of materials and where they will be housed for reference.

- Develop a timeline and lead agency for an annual review of these resource materials for relevancy and accuracy and notify all stakeholders of revisions and additions.

**Identified Subgoals under Goal #2 with Recommended Action Plans:**

**Goal #2:** *All children who are D/HH and their families experience timely access to services coordinators who have specialized knowledge and skills related to working with individuals who are D/HH.*

 Service Coordinators oversee the implementation of the IFSP from initial evaluations to ongoing service delivery to transition into school programming. They also coordinate with agencies and credentialed providers who are enrolled in the Early Intervention program. There are a number of studies that have identified parents’ needs and experiences related to children hearing loss, but few studies actually investigate the exact information parents receive. Since one crucial role of the Service Coordinator is to match a family with a skilled provider who has the training to meet the outcomes each family desires, Illinois seeks to coordinate the delivery of these resources so all families receive information they need to make informed choices. Each CFC has at least one Designated Service Coordinator (DSC), who either serves as case manager or serves as a resource to other service coordinators for children with hearing or vision loss. DSCs have received additional training related to hearing loss in past years, but this training has not been maintained and turnover of Service Coordinators in each CFC is not tracked systematically.

States must report their program’s progress toward meeting early learning standards, and the Service Coordinator shares in this measure of accountability. These DSCs for children who are D/HH are the ones who help families select a qualified service provider who will support the families’ needs, concerns, and outcomes. Professionals must have the appropriate knowledge, skills, and dispositions to make a positive difference in child and family outcomes. (14) Workgroup discussions related to current practice identified several key areas that needed to be addressed to meet this recommended JCIH goal. Most of the action plans centered on ongoing support and training of the DSCs who are currently working in each of the CFC offices and developing systems for new Service Coordinators to access information as needed. Illinois needs a structured training program for service coordinators to provide tools and resources necessary to care for, guide, and educate families of children with hearing loss. By providing this training and ongoing support, these case managers can help reduce family stress, offer an enhanced quality of care, and portray a consistent message between families/offices as well as reduce the chances of a family “falling through the cracks.” Oftentimes Service Coordinators are one of the first points of contact with the family, who is learning about a new system that may be of benefit following medical diagnosis.

**The recommended action steps are:**

A. Within six months, initiate Designated Service Coordinator training for at least five and no more than seven staff throughout each of the 25 CFC offices. The current number of Designated Service Coordinators is 44, as reported in August 2016. Training topics may include: type of HL and types of amplification, communication modes; types of services and differences that various professionals offer; types of services parent-to-parent support can offer; Deaf Mentor service and referral; terminology; basic audiogram knowledge; populations that are at- risk; authorization process for AT—including all accessories; guidelines for audiology evaluations/ear molds/ batteries; and importance of EHDI consent form completion.

- Illinois School for the Deaf (ISD) Outreach will develop these training materials and the Bureau will review and approve.

- A timeline for implementation will be established as well as a location for archived training materials.

- Credit will be approved through EITP for Service Coordinators; and must have a pre-post survey.

- Development of webinar(s) for review and for new Service Coordinators.

- Committee will review existing materials developed for previous Designated Service Coordinator training,

B. Illinois State University-sponsored BRIDGES conference planning committee will develop and implement a DSC track at the conference to be held June 19-20, 2017.

 - Work with Bureau to advertise to CFC Program Managers to allow staff to attend.

 - Apply for CEU and CPDU credit for Service Coordinators.

C. Initiate discussion with state agencies for continued BRIDGES conference in 2018.

D. Investigate hosting monthly webinar training on one key issue covered in more depth. Archive these on the Sound Beginnings website for others to access. Credit should apply for those watching archived training. Data should be kept on all who access the training.

- Selection of appropriate qualified service providers to meet family needs and outcomes should be a priority topic.

E. Link regional DSCC coordinators with specialized training and resources in the areas of speech and language, communication, early development and the impact of hearing loss, and audiology with child and family connection offices for increased collaboration of family supports.

**Identified Subgoals under Goal #3 with Recommended Action Plans:**

**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.*

“Families who access timely and comprehensive services from professionals knowledgeable about early development, communication, and language are more likely to witness greater progress in many areas of development than those without similar opportunities” (Kennedy, McCann, Campbell, Kimm, & Thornton 2006; Moeller 2000, 2007; Yoshinaga-Itano 2003) (15).

Recommendations for all early intervention programs and providers have been endorsed by many professional organizations, e.g., American Speech- Language-Hearing Association (ASHA 2008a); National Association for the Education of Young Children (Copple & Bredekamp 2009); and the Division for Exceptional Children of the Council for Exceptional Children (Sandall, Hemmeter, Smith, & McLean 2005). (16) Using data collected from Goal 3 and its subgoals, the Workgroup evaluated what was working in the state system(s) related to professional qualifications and core knowledge and skills and where improvements were needed.

Research states that children who are identified with hearing loss early and begin intervention at young ages have better language skills compared to later identified children or those who begin intervention in later months. Even with the advances in identification and screening and an earlier start with interventions, language skills can “vary greatly and are lower, on average, compared with children with typical hearing (Moeller 2000; Niparko, et al., 2010; Yoshinaga-Itano, et al., 1998) (17-18-19). Additionally, the language gap increases as the age of beginning intervention increases (Moeller 2000). This variation in the language skills of children with hearing loss, even when services begin early, speaks to the quality of intervention being delivered and whether aspects of early intervention that support language development need improving.

Illinois has entry qualifications for all service providers who want to work in the EI system. These include documentation of training in developmental areas and system enrollment for Illinois (Appendix 5). Whereas specialized skills for working with children who are D/HH and their families are recommended, Illinois has a specialized provider to be able to support these families. A professional with a four-year degree in Deaf Education may become a Developmental Therapist/Hearing (DT/H). The DT/H educators understand the communication and language needs, auditory development, assistive listening technology, and typical child development and use this knowledge to implement interventions fostering parent-child communication. DT/Hs are automatically enrolled as a provider who may deliver aural rehabilitation services. While teachers of deaf children have expertise regarding the effects of being deaf of or hard-of-hearing on communication and language development, some may lack the specialized knowledge and skills required to work with the new population of infants and toddlers and their families who are diagnosed at earlier ages and receive amplification at earlier ages than before. With the rise of young children receiving cochlear implants and families needing more specialized information and support, many professionals must seek additional training. Per definition, a Speech and Language Pathologist in Illinois may also be called upon to provide aural rehabilitation. Under the service descriptions used in Illinois, professionals in both disciplines are able to provide aural rehabilitation. The definition of this service is found with the description of audiology, aural rehabilitation, and other related services in the Illinois EI Provider Handbook. “Audiology, aural rehabilitation, and other related services include: 1) identification of children with hearing loss using appropriate audiological screening techniques; 2) determination of the range, nature, and degree of hearing loss and communication functions by use of audiological evaluation procedures; 3) referral for medical testing and other services necessary for the habilitation or rehabilitation of children with hearing loss; 4) IFSP development; 5) provision of auditory training, aural rehabilitation, speech reading and listening device orientation/training, and other related services; and 6) determination of the child's need for individual amplification including selecting, fitting, and dispensing appropriate listening and vibrotactile devices, and evaluating the effectiveness of those assistive technology devices. Family training, education, and support provided to assist the family of a child eligible for services in understanding the special needs of the child as related to audiology and aural rehabilitation services and enhancing the child's development are integral to this service.” (20) The Workgroup recognized the benefit of the Illinois credential process and the opportunities available for ongoing professional development. Action plans were developed to build on existing programs and services.

The recommended action steps are:

1. Investigate additional assessments meeting Aural Rehabilitation requirements for an approved assessment tool through EI that providers may use while performing Aural Rehabilitation initial evaluations and ongoing assessments.

- Review the approved assessment tool listing through EI and differentiate Audiological assessments performed in clinic and listening assessments performed by service providers.

- Target the specific audience, Including DT/H and ST, for approved Early Intervention training.

1. Initiate dialog with EITP for additional training specific to D/HH. Topics to include are:

- Communication modalities, supports, and best practices: ASL, Cued Speech, Listening and Spoken Language, and Total Communication.

- Secure qualified trainers for presentation(s).

- Ongoing Professional Development – best practices and models.

1. Increase the visibility of supports available for communication and listening skill development so providers in EI can self-evaluate and plan ongoing professional development to meet the needs of families and children.
2. Investigate the ASL modules developed by Rachel Coleman and NCHAM and incorporate into initial evaluators training. Post on Sound Beginnings for ongoing service providers to utilize.
3. Investigate a system to identify skill set(s) of providers and make it available to Service Coordinator statewide.

- Define Aural Rehabilitation services and who is eligible and qualified to provide.

- Example: ST are automatically allowed to perform AR evaluations but Service Coordinators are not able to authorize them through the current Cornerstone system.

1. Investigate ways to identify Service Providers in EI who have experience working with children who are deaf or hard of hearing. Include the SLP database and DT/H database.
2. Utilize existing positions in CFC offices (Social Emotional Consultant, Parent Liaison, AT Coordinator) for the training and marketing of new initiatives for family engagement and support.

**Identified Subgoals under Goal #7 with Recommended Action Plans:**

**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.*

Second part of Goal 7:  *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. Considering this information, please rank each of the following subgoals.*

As outlined by the Joint Commission in Infant Hearing, hearing loss of any degree – including mild hearing loss, unilateral hearing loss, and fluctuating hearing loss - can cause delays in social-emotional, language, and cognitive development. Unilateral hearing loss poses additional risks, including poor sound localization, which can affect a child’s physical safety, and speech perception in noise. Regardless of the severity of the hearing loss, sufficient data has shown that cumulative developmental delays lead to poor academic outcomes. Thus, there is a need to provide sufficient support to all children with any degree of hearing loss in order to optimize their potential.

For children with less severe hearing loss, there is often inconsistent use of hearing devices, which is largely due to the fact that children show some awareness to sound without using hearing aids. Standard practice is to request audiological evaluations and hearing device evaluations after initial diagnosis only when there is concern about a child’s development. Children with mild, unilateral, and/or fluctuating hearing loss, however, often have subtle problems understanding the sounds around them, including language. These problems can easily go unnoticed by their caregivers and early intervention providers and are often only detected when there is an overt behavior change in the children. As a result, children may run the risk of delayed development, even in the presence of intervention, because their understanding of sound is impaired to a greater degree than previously thought.

Families receive confirmation that their child is deaf or hard-of- hearing from healthcare professionals, who understandably focus on the medical aspect of the diagnosis, such as the fit of hearing aids, genetic counseling, and referrals to additional medical professionals. Illinois seeks to integrate audiology services and audiologists with interventionists and service coordinators for a more comprehensive service delivery model.

One solution to minimize developmental delays in children with all degrees of hearing loss is to better educate caregivers and providers about hearing loss and the potential signs that their child is struggling to hear. A second solution is to provide mechanisms that allow for more frequent audiological monitoring for children, especially those in special populations that traditionally have fluctuating hearing loss (e.g., children with Down syndrome).

The recommended action steps are:

7.1 *Refer all children with unilateral or bilateral hearing loss to EI for evaluation and consideration of enrollment. If a 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.*

A. The state assessment survey indicated this as an area of strength for families being referred to Early Intervention. However, more data needs to be collected as to the completion of initial evaluations by credentialed evaluators with experience with children who have hearing loss and continued participation in Early Intervention.

B. Cross reference materials and resources that audiologists disseminate with the resources that the initial Aural Rehabilitation evaluators provide at initial evaluations and initial IFSP meetings.

- CHOICES for Parents notebook made available to all initial evaluators and audiologists.

- Provide training to all providers about the availability and recommended resources that all families should receive.

7.6 *Develop and disseminate information about the use of amplification for children with hearing loss prepared by consulting audiologists with expertise with infants/children.*

A. Define bone conduction and Bone Anchored Hearing Aid technology and access avenues related to EI relevant to the infant and toddler population.

- Collaborate with EI AT Coordinator for procedures and documentation necessary.

B. Develop webinars to allow enrolled audiologists opportunity to become familiar with EI procedures and authorized visits and equipment.

C. Use audiologists to develop webinar(s) with a focus on the special needs population and its potential for hearing loss and submit application to EITP for training.

- Each webinar developed will be submitted to the Early Intervention Training Program so professional development credit may be obtained.

D. Develop audiologist participation on committees to design and implement Designated Service Coordinator training.

7.9 *Consider amplification if the hearing loss has remained for six months, even if it is temporary, to accomplish this auditory access. This group also includes children with cleft palate or Down syndrome, who are highly at risk for chronic fluctuating middle ear effusion.*

A. Pursue discussions with EI Bureau to clarify number of audiological appointments children may receive through the EI system. Build this information into DSC training and initial evaluator training so that when concerns arise at a six-month or annual assessment for a child in EI without earlier diagnosed hearing loss, an authorization may be sought for a hearing test.

**Summary:**

Illinois is in a position to positively change how EHDI and Early Intervention systems interact to support families and positive outcomes for children who have hearing loss. The Workgroup developed recommended action plans related to each of the identified goals. The process of self-assessment provided a measurable way to make quality improvements in identified areas. Future activities may be necessary to initiate and maintain these action plans. Workgroup participants were steadfast in their commitment to learning and problem solving as activities generated will affect outcomes for children who are deaf or hard of hearing and their families.

**Appendix 1:** American Academy of Pediatrics, Joint Committee on Infant Hearing. Year 2007 position statement: principles and guidelines for early hearing detection and intervention programs. *Pediatrics*, 2007; 120(4):898–921

**Appendix 2:** Early Hearing Detection and Intervention System Self-Assessment; April, 2015.

**Appendix 3**: Illinois Early Hearing Detection and Intervention System Self-Assessment

**Appendix 4:** Supplementary Materials Provided to Illinois Workgroup Stakeholders

**Appendix 5:** Qualifications of EI Providers

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1. July 1, 2015 through June 30, 2016 [↑](#footnote-ref-1)
2. The proportion of newborns with a positive screening result who are then referred to a pediatric audiologist for diagnostic evaluation. [↑](#footnote-ref-2)