

**Early Hearing Detection and Intervention
Hearing Screening and Follow-up Survey**

Reinstatement with Change

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Attachment 3:

National EHDI Goals

National Goals and Program Objectives for the Early Hearing Detection and Intervention (EHDI) Tracking and Surveillance System

In collaboration with state participants and representatives from other federal and national agencies, CDC developed EHDI program objectives and performance indicators. Numerous sources were used to identify these objectives and indicators, such as state guidelines, the Joint Committee on Infant Hearing's (JCIH) Position Statement and the American Academy of Pediatrics (AAP) position statement on EHDI. It is the responsibility of the states to put these objectives into a feasible timeline.

Goal 1. All newborns will be screened for hearing loss before 1 month of age, preferably before hospital discharge.

Program Objectives	Performance Indicators
<p>1.1 <i>Universal screening.</i> All birthing facilities will have a universal newborn and infant hearing screening (UNHS) program that screen all newborns. Small hospitals that do not screen newborns will refer infants to a screening program.</p>	<p>a. Number/percent of birthing hospitals in the state that screen at least 98% of infants before discharge. b. Number/percent of small hospitals that do not screen but have plans for referral to a screening program including designation of responsible staff position(s) and timeline. c. Number/percent of infants screened before hospital discharge. d. Number/percent of infants screened before 1 month of age. e. Number/percent of infants whose families refuse screening.</p>
<p>1.2 <i>Information on newborn hearing and the screening process.</i> All birthing facilities will have linguistically appropriate and culturally sensitive brochures/materials to inform parent(s) or guardians of newborns about the newborn hearing and screening process before the infant is screened.</p>	<p>a. Number/percent of pregnant women that received EHDI information before delivery. b. Number/percent of new parents that receive EHDI information in the hospital at the time of delivery. c. Number/percent of hospitals that provide information packets in Spanish and/or other languages where the minority is 5% or more.</p>
<p>1.3 <i>Demographic data.</i> All hospitals will collect demographic data such as race/ethnicity, educational level of the mother, and type of insurance covered before hospital discharge.</p>	<p>a. Number/percent of infants in each racial/ethnic group. b. Percent of infants whose mothers are in each category of level of education. c. Number/percent of mothers in each insurance category.</p>
<p>1.4 <i>Out of hospital births.</i> States will have a mechanism to ensure that infants not born in birthing hospitals will receive a hearing screening.</p>	<p>a. Number/percent of infants born out of hospital. b. Number/percent of infants born out of the hospital that received a hearing screening before one month of age.</p>
<p>1.5 <i>Financial barriers.</i> Each state will develop a system to reduce/eliminate financial barriers to screening.</p>	<p>a. Published guidelines to reduce financial barriers that include information to parent on how to receive financial help or free screening and/or diagnostic services. b. Number of hospitals or other relevant organizations to which the guidelines were distributed, including designation of responsible staff and timelines.</p>

1.6 <i>Reporting.</i> Results of the hearing screening will be provided to all parents and to the infant's primary care provider (PCP).	a. Forms and stated protocol for providing screening results to parents and PCP are available.
1.7 <i>Linkage and Referral to Audiologic follow-up.</i> Each state will identify a linkage system to ensure that all infants who do not pass the hearing screening will have appropriate referral for diagnostic evaluation.	a. Number/percent of infants that did not pass the initial inpatient or outpatient screen and are referred for diagnostic audiologic evaluation.
1.8 <i>Education/Training.</i> Hospitals or EHDl program will have a training plan for all service providers including screeners (inpatient and outpatient), nurses, and physicians.	a. Yearly or semi-annual list of training sessions completed (or planned) for screeners, nurses, and physicians.
1.9 <i>Screening protocols.</i> Hospitals will have written hearing screening protocols that include standard policies, procedures for screening, and appropriate forms.	a. Copy of hearing screening protocols.

Goal 2. All infants who screen positive will have a diagnostic audiologic evaluation before 3 months of age.

Program Objectives	Performance Indicators
2.1 <i>Audiologic evaluation.</i> Audiologists will administer a comprehensive audiologic evaluation to all infants who screen positive for hearing loss before 3 months of age to confirm infant/child hearing loss including type, configuration, and degree.	<ul style="list-style-type: none"> a. Number/percent of infants that screened positive and received a comprehensive audiologic evaluation before 3 months of age. b. Number/percent of infants with bilateral or unilateral hearing loss. c. Number/percent of infants with permanent conductive, sensorineural or auditory dys-synchronous hearing loss. d. Number/percent of infants with mild, moderate, severe, moderately severe, or profound hearing loss. e. Number/percent of infants referred for audiologic evaluation but are lost to follow-up. f. Number/percent of infants at risk for developing late onset hearing loss that are lost to follow-up. g. Number/percent of infants referred for audiologic evaluations that were not screened for hearing loss.

2.2 <i>Evaluation protocols.</i> Each state will develop and make accessible protocols/guidelines for appropriate diagnostic audiologic evaluation and recommendations for management (e.g. amplification, rehabilitation). These guidelines will be developed with state and local audiologists' input and based on current national guidelines.	<ul style="list-style-type: none"> a. Documented list of acceptable measures to be included in the test battery for the identification of hearing loss and minimum frequency of evaluation to monitor the hearing sensitivity of all infants/children identified with hearing loss and all infants/children identified at risk for late-onset, progressive or acquired hearing loss. b. Copy of diagnostic management (e.g. amplification, rehabilitation) protocol that is based on current national guidelines c. Number/percent of audiologists that have and follow
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	<p>state protocols when conducting audiologic evaluations for infants and children.</p> <p>d. Copy of diagnostic management protocol (e.g. amplification, rehabilitation) that is based on current national guidelines (JCIH, ASHA, AAA).</p>
<p>2.3 <i>List of diagnostic audiologic providers.</i> Each state will maintain a current resource list of diagnostic centers and/or pediatric audiologists who have experience/expertise in administering diagnostic audiologic evaluations for infants, according to the protocol/guidelines.</p>	<p>a. List of diagnostic centers and/or audiologists that have experience or expertise in conducting pediatric audiologic assessments.</p> <p>b. Number of centers/audiologists that have appropriate equipment for diagnostic evaluation of infants.</p> <p>c. Number of hospitals or referral personnel that maintain a list of diagnostic centers or audiologists.</p>
<p>2.4 <i>Linkage to appropriate follow-up.</i> Each state will identify a linkage system to ensure that families of infants identified with hearing loss will have appropriate referral to medical, audiologic, and intervention services, according to state resources.</p>	<p>a. Number/percent of infants identified with hearing loss referred to medical specialists, such as otolaryngologists, ophthalmologists, and geneticists.</p> <p>b. Number/percent of infants with hearing loss that are referred to early intervention services, including counseling and support services.</p> <p>c. Number/percent of infants with hearing loss that are referred to on-going audiologic evaluations and services.</p>
<p>2.5 <i>Education/Training for Audiologists.</i> Each state will develop an education/ training plan for audiologists to ensure competency in pediatric evaluation, management, and family counseling.</p>	<p>a. Documented training plan for audiologists.</p> <p>b. Number of audiologists trained or offered opportunity.</p>
<p>2.6 <i>Education/Training for Other Providers.</i> Each state will develop an education/training plan for primary care providers, public health nurses and others related to the importance and process of audiologic evaluation.</p>	<p>a. Documented training plan for other providers.</p> <p>b. Number of professionals trained.</p>
<p>2.7 <i>Information on the audiologic evaluation process.</i> Parents and guardians will be informed in a culturally sensitive and language appropriate manner about the diagnostic audiologic evaluation process and report.</p>	<p>a. Documentation of language-appropriate materials and interpreter services to describe audiologic services and reports.</p> <p>b. Documented plans for disseminating materials.</p> <p>c. Number of materials distributed.</p>

Goal 3. All infants identified with hearing loss will receive appropriate early intervention services before 6 months of age (medical, audiologic, and early intervention).

Program Objectives	Performance Indicators**
<p>3.1 <i>Medical services.</i> All infants identified with hearing loss will receive appropriate medical services, such as primary care, visual, genetic services, and counseling before 6 months of age.</p>	<p>a. Number/percent of infants with hearing loss that received appropriate medical services before 6 months of age from:</p> <ul style="list-style-type: none"> -primary care; -otolaryngologists; -ophthalmologists; and -geneticists/genetic counselors.
<p>3.2 <i>Early intervention services.</i> Each state will ensure</p>	<p>a. Number/percent of infants with hearing loss were</p>

<p>that all infants and children with documented hearing loss will receive appropriate early intervention services from Part C or other state approved intervention services. Service coordination will be provided to eligible children.</p>	<p>enrolled in an intervention program before 6 months of age</p> <p>b. Number/percent of infants/children with hearing loss that received family support information about early intervention services.</p> <p>c. Number/percent of eligible infants/children categorized by hearing loss that have a signed IFSP or an equivalent intervention plan.</p> <p>d. Number/percent of infants that are lost to follow-up after identification.</p> <p>e. Number/percent of infants with hearing loss eligible for Part C services with</p> <ul style="list-style-type: none"> -mild hearing loss; -moderate hearing loss; -moderately-severe hearing loss; -severe hearing loss; or -profound hearing loss.
<p>3.3 <i>Audiologic services.</i> All infants identified with hearing loss will receive appropriate audiologic services before 6 months of age.</p>	<p>a. Documentation that confirms that families of children with hearing loss received information on communication and amplification options.</p> <p>b. Documentation of plan for management of each infant's/child's assistive technology which include, at a minimum, use of probe microphone measures and recommendations for frequency of evaluation.</p> <p>c. Documentation of protocols/guidelines for management of each infant/child's aural habilitation/rehabilitation</p> <p>d. Number/percent of infants fitted with personal amplification before 6 months of age</p>

**Some states may need to differentiate between Part C eligible and non-eligible infants.

<p>3.4 <i>Policy statement for stakeholders.</i> Each state will adopt and distribute as appropriate a policy regarding the rights of every family to choose the communication modes/methods that is most appropriate for their child.</p>	<p>a. Documentation of procedural safeguards regarding the rights of families when choosing a communication mode for their child.</p> <p>b. List of resources and contacts to assist families in learning about various communication options, enabling them to make more informed decisions.</p> <p>c. Documented plans for distributing the resource list and procedural safeguards to families identified by the newborn hearing screening program.</p>
<p>3.5 <i>Resource guide.</i> All states will develop a comprehensive, family-friendly Resource Guide that will include: material from a variety of sources; a list of relevant web sites; a list of state contact people. The Guide will be available in print as well as on a web site and in major languages used in the state, pending available resources.</p>	<p>a. Number/percent of parents/guardians of infants with a confirmed hearing loss that reached 6 months of age within the last calendar year that received a copy of the state resource guide.</p> <p>b. Documentation of resource guides in any language spoken by 5% or more of the population in that state.</p> <p>c. The state resource guide will include a list of questions for parents to ask in assessing the philosophy and practices of programs they consider for their child.</p>

<p>3.6 <i>Membership of IFSP or other Intervention Team.</i> All families who have a child with identified hearing loss should have an individual on their intervention team who has knowledge, experience, and expertise with the issues related to children who are deaf or hard of hearing.</p>	<p>a. Number/percent of intervention teams that include individuals with professional preparation and/or professional experience working with children with hearing loss.</p>
<p>3.7 <i>Education/Training.</i> States will provide opportunities to Part C and other intervention services to receive training on specific issues related to deafness and hearing loss.</p>	<p>a. Documentation of implemented and planned training sessions for Part C or other intervention service providers.</p>
<p>3.8 <i>Quality intervention systems.</i> States shall ensure that high quality early intervention systems are available, including those that meet the needs of diverse populations and children with additional disabilities.</p>	<p>a. List of intervention services that describe available services for diverse populations. b. Documentation of services for children with hearing loss who also have other disabilities.</p>
<p>3.9 <i>Recommendations for early intervention providers.</i> States shall develop a set of recommendations for Early Intervention Providers who work with children who are deaf or hard of hearing and their families that include: -identification of objective sources of information for families to learn about communication options. -guidelines for monitoring the communication and social skill development of the child with hearing loss at 6-month intervals. -identification by each early intervention program of personnel within their staffs who are specialists in deaf and hard of hearing issues. -process for linkage to family-to-family support within an early intervention system. -list of preschool program options that are particularly prepared to serve children who are deaf or hard of hearing, and inclusion of this information in the preparation of the family for transition at age 3.</p>	<p>a. Documentation of distributions of a resource guide that presents balanced information on communication options. b. Documented test scores for communication and social skill development at 6-month intervals. c. Documentation of annual updated guidelines. d. Number/percent of families referred to and involved in parent-to-parent support program.</p>
<p>3.10 <i>Parent participation.</i> Each state will ensure families of children with hearing loss have an opportunity to actively participate in the EHDI system.</p>	<p>a. Number/percent of parents involved in their child's program planning, evaluation, or monitoring. b. Number/percent of parents on the EHDI Advisory Board.</p>

Goal 4. All infants and children with late onset, progressive or acquired hearing loss will be identified at the earliest possible time.

Program Objectives	Performance Indicators
<p>4.1 <i>Risk factors:</i> Each hospital, audiologist and other providers will identify infants with risk factors for hearing loss and transmit to state.</p>	<p>a. Number/percent of infants with one or more risk factors.</p>
<p>4.2 <i>Monitoring of at-risk infants.</i> Each state will have a mechanism in place to monitor the hearing status of</p>	<p>a. Number/percent of infants with risk factors that are</p>

infants at risk for late onset and progressive hearing loss.	re-screened by 6 months.
4.3 <i>Acquired hearing loss</i> . Each state will have a mechanism in place to identify and provide follow-up services for infants and children with acquired hearing loss.	a. Number/percent of infants/children identified with acquired hearing loss.

Goal 5. All infants with hearing loss will have a medical home as defined by the American Academy of Pediatrics.

Program Objectives	Performance Indicators
5.1 <i>Medical Home</i> . Each infant with a confirmed hearing loss will have an identified primary care provider before 3 months of age.	<p>a. Number/percent of infant records that include name of the infant's primary care provider.</p> <p>b. Documentation that the results of the infant's audiologic evaluation were sent to their primary care provider.</p> <p>c. Number of pediatricians, family physicians, nurse practitioners, midwives, etc. that provide primary care for infants/children with hearing loss.</p>
5.2 <i>Collaboration with Early Intervention</i> . Each medical home will collaborate with the early intervention system and the family to develop a plan to connect families to advocacy groups, parent support networks, and parent to parent support.	a. Documentation in each family plan or Individual Family Service Plan of collaboration between the early intervention systems and the medical home.
5.3 <i>Unbiased information</i> . Each state will develop resources that can be shared with the medical homes and families to provide unbiased information.	a. Documentation that Resource Guide is provided to physicians and other primary care providers describing unbiased information regarding early intervention strategies.
5.4 <i>Education</i> . In partnership with parents of children with hearing loss, states will develop a plan to provide education about the state EHDI program to medical homes.	<p>a. Documentation of plan to provide information on EHDI program to each infant/child's medical home.</p> <p>b. Number/percent of each type of medical home (physician, midwife, etc.) that receive written information and/or attend a session about the EHDI Program</p> <p>c. List of medical homes collaborating with state EHDI program</p>
5.5 <i>Parent input</i> . Each state will have a mechanism for obtaining parent feedback and including parents in the process of development and evaluation processes for the medical home.	<p>a. Number of parents participating in the development and evaluation of the medical home.</p> <p>b. Results of survey or other mechanism to obtain parent feedback</p>
5.6 <i>Continuous care</i> . Each state will have a mechanism for identifying and tracking the infant's primary care provider at key intervals, regardless of insurance status.	<p>a. Number/percent of infants with documented medical home.</p> <p>b. Updated documentation of who the primary care provider is at birth, 1, 3, 6, 12 months and yearly.</p>

Goal 6. Every state will have a complete EHDI Tracking and Surveillance System that will minimize loss to follow-up.

Program Objectives	Performance Indicators
6.1 <i>Comprehensive system.</i> Each state will have a computerized system that maintains current information on hearing screening for every infant, evaluation for all infants/children who do not pass the screening, and interventions for every infant and child from birth through 5 years of age with hearing loss.	a. Written description of computerized system b. Printouts and reports of screening, evaluation, and intervention data.
6.2 <i>Policies and procedures.</i> Each state will have written policies and procedures regarding operation of the EHDI Tracking and Surveillance System.	a. Documentation of policies and procedures manual.
6.3 <i>Privacy and confidentiality.</i> Each state will develop policies, procedures, and informed consent requirements regarding privacy and confidentiality of data in the EHDI Tracking and Surveillance System.	a. Documentation of policy and procedures on informed consent requirements.
6.4 <i>Include all births.</i> Each state will ensure that all live births in the state are included in the state EHDI Tracking and Surveillance System by matching with the state's birth certificates registry as allowed by state policy.	a. Number of live-born infants. b. Number/percent of infants screened. c. Documentation of number/percent of matches with vital records.
6.5 <i>Risk factors for hearing loss.</i> The state EHDI Tracking and Surveillance System will ascertain risk factors for hearing loss for every infant by linkage with other state data systems, such as hospital records, birth certificates, birth defects, metabolic screening, immunizations, etc.	a. Number/percent of infants with risk factors. b. Number and type of risk factors for each infant.
6.6 <i>Newborn hearing screening results.</i> The state EHDI Tracking and Surveillance System will capture all hearing screening results at birthing hospital within [a week] after discharge or transfer.	a. Report on number/percent of infants screened that includes: results for each ear, technology used, and age at screening.
6.7 <i>Reporting mechanism for health care providers.</i> Each state will provide a mechanism for hospitals, audiologists and other health care providers to report hearing screening results, evaluations and interventions.	a. Number of health care providers that have protocols for reporting hearing screening results, evaluations and interventions. b. Number of health care providers reporting hearing screening results to the state.
6.8 <i>Identifying children who need screening and follow-up.</i> The state EHDI Tracking and Surveillance System will be able to identify, on a [weekly] basis, all infants and children who need initial hearing screening, repeat testing, evaluation, follow-up or intervention.	a. Number/percent of infants/children needing follow-up: -referred for second screening -missed screening -repeat -referred for diagnostics -referred for early intervention b. Number/percent of infants/children that received

	follow-up.
6.9 <i>Access to information.</i> The state EHDI Tracking and Surveillance System will allow case managers and authorized health care providers to access relevant information about infants and children.	a. Written plan to allow access for case managers and authorized health care providers to relevant information.

Goal 7. Every state will have a comprehensive system that monitors and evaluates the progress towards the EHDI Goals and Objectives.

Program Objectives	Performance Indicators
7.1 <i>Advisory Committee.</i> Each state's advisory committee will meet routinely to provide guidance on the EHDI system. The committee should include professionals, individuals with hearing loss, families with children who have permanent hearing loss, and others to provide guidance on the development and evaluation of the EHDI system.	a. List of Advisory Committee members. b. Minutes of Advisory Meeting.
7.2 <i>Monitoring and Evaluation.</i> Each state EHDI program will develop a program evaluation plan in collaboration with the program Advisory Committee, to ensure progress towards national and state program goals and objectives.	a. Annual evaluation reports that includes accomplishments of national and state program goals and objectives.
7.3 <i>Feedback from families.</i> The state EHDI program will obtain feedback from parents on the EHDI process	a. Conduct survey of parent concerns and issues. b. Disseminate results of parent survey to stakeholders.
7.4 <i>Surveillance of Follow-up Services.</i> Each state will ensure that infants and children with hearing loss will receive on-going appropriate follow-up services.	a. Number/percent of infants/children with hearing loss that received appropriate on-going medical services from primary care, otolaryngologists, ophthalmologists, geneticists/genetic counselors. b. Number and age of infants/children fitted with implants. c. Number/percent of infants/children using each mode of communication, e.g. sign language, oral, cued speech at 6-month intervals. d. Number/percent of infants/children achieving communication and social skills scores commensurate with their cognitive abilities age at 1, 3, 5, and 7 years of age. e. Number/percent of infants/children with hearing aids that receive follow-up visits at 2-month intervals until age 2 and 3-month intervals until age 3.