

***National Goals, Program Objectives, and
Performance Measures 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 and the position statements of the Joint Committee on Infant Hearing (JCIH) and the American Academy of Pediatrics (AAP). States are responsible for putting these objectives into a feasible time line.

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 screens all newborns. Small hospitals that do not screen newborns will refer infants to a screening program.</p>	<p>a. Number and percent of birthing hospitals in the state that screen at least 98% of infants before discharge. b. Number and percent of small hospitals that do not screen but have plans for referral of infants to a screening program, including designation of responsible staff positions(s) and timeline. c. Number and percent of infants screened before hospital discharge. d. Number and percent of infants screened before 1 month of age. e. Number and 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 or other 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 and percent of pregnant women that received EHDI information before delivery. b. Number and percent of new parents that receive EHDI information in the hospital at the time of delivery. c. Number and percent of hospitals that provide information packets in Spanish, or other languages spoken by at least 5% of the population.</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 and percent of infants in each racial/ethnic group. b. Percent of infants whose mothers are in each category of level of education. c. Number and percent of mothers in each insurance category.</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.	a. Number and percent of infants born out of hospital. b. Number and percent of infants born out of the hospital that received a hearing screening before one month of age.
1.5 <i>Financial barriers.</i> Each state will develop a system to reduce/eliminate financial barriers to newborn hearing screening.	a. Published guidelines to reduce financial barriers that include information for parents 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.
1.6 <i>Reporting.</i> Results of the hearing screening will be provided to the infant's parents and 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 and percent of infants that do not pass the initial inpatient or outpatient screening and are referred for diagnostic audiologic evaluation.
1.8 <i>Education and training.</i> Hospitals or EHDI program will have a training plan for all service providers, including screeners (inpatient and outpatient), nurses, and physicians.	a. Yearly or semiannual 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.	a. Number and percent of infants who screened positive and received a comprehensive audiologic evaluation before 3 months of age. b. Number and percent of infants with bilateral or unilateral hearing loss. c. Number and percent of infants with permanent conductive, sensorineural, or auditory dys-synchronous hearing loss. d. Number and percent of infants with mild, moderate, severe, moderately-severe, or profound hearing loss. e. Number and percent of infants referred for audiologic evaluation who were lost to follow-up. f. Number and percent of infants at risk of developing late onset hearing loss who were lost to follow-up.

	g. Number and percent of infants referred for audiologic evaluations who were not screened for hearing loss.
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<p>2.2 <i>Evaluation protocols.</i> Each state will develop and make accessible protocols and guidelines for appropriate diagnostic audiologic evaluation and recommendations for management (e.g., amplification, rehabilitation). These guidelines will be developed with input from state and local audiologists and based on current national guidelines.</p>	<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 and children identified with hearing loss and all infants and 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 (JCIH, ASHA, AAA). c. Documentation of availability of protocols for audiologists in a variety of formats.
<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 and expertise in administering diagnostic audiologic evaluations for infants, according to the protocol and guidelines.</p>	<ul style="list-style-type: none"> a. List of diagnostic centers and audiologists that have experience or expertise in conducting pediatric audiologic assessments. b. Number of centers and audiologists that have appropriate equipment for diagnostic evaluation of infants. c. Number of hospitals or referral personnel that maintain a list of diagnostic centers or audiologists.
<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>	<ul style="list-style-type: none"> a. Number and percent of infants identified with hearing loss referred to medical specialists, such as otolaryngologists, ophthalmologists, and geneticists. b. Number and percent of infants with hearing loss who are referred to early intervention services, including counseling and support services. c. Number and percent of infants with hearing loss who are referred to ongoing audiologic evaluations and services.
<p>2.5 <i>Education and 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>	<ul style="list-style-type: none"> a. Documented training plan for audiologists. b. Number of audiologists trained.
<p>2.6 <i>Education and Training for other providers.</i> Each state will develop an education and training plan for primary care providers, public health nurses, and others on the importance and process of audiologic evaluation.</p>	<ul style="list-style-type: none"> a. Documented training plan for other providers. b. Number of professionals trained.
<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>	<ul style="list-style-type: none"> a. Documentation of language-appropriate materials and interpreter services to describe audiologic services and reports. b. Documented plans for disseminating materials. c. Number of materials distributed.

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 screening, genetic services, and counseling before 6 months of age.</p>	<p>a. Number and percent of infants with hearing loss who received appropriate medical services before 6 months of age from: primary care, otolaryngologists, ophthalmologists, and geneticists/genetic counselors.</p>
<p>3.2 <i>Early intervention services.</i> Each state will ensure 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>a. Number and percent of infants with hearing loss who were enrolled in an intervention program before 6 months of age b. Number and percent of infants and children with hearing loss who received family support information about early intervention services. c. Number and percent of eligible infants and children categorized by hearing loss who have a signed IFSP or an equivalent intervention plan. d. Number and percent of infants who are lost to follow-up after identification. e. Number and percent of infants with hearing loss eligible for Part C services with mild hearing loss, moderate hearing loss; moderately-severe hearing loss, severe hearing loss, or profound hearing loss.</p>
<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. b. Documentation of plan for management of each infant's and child's assistive technology that includes, at a minimum, use of probe microphone measures and recommendations for frequency of evaluation. c. Documentation of protocols and guidelines for managing the aural habilitation or rehabilitation of each infant or child. d. Number and 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 and methods that are most appropriate for their child.</p>	<p>a. Documentation of procedural safeguards regarding the rights of families when choosing a communication mode for their children. b. List of resources and contacts providing information about various communication options to enable families to make more informed decisions. 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 and percent of parents and guardians of infants who have a confirmed hearing loss that reached 6 months of age within the last calendar year that received a copy of the state resource guide. b. Documentation of resource guides in any language spoken by 5% or more of the population in that state. 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 and percent of intervention teams that include individuals with professional preparation and experience working with children with hearing loss.</p>
<p>3.7 <i>Education and 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 make sure 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:</p> <ul style="list-style-type: none"> -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 linking 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 years. 	<ul style="list-style-type: none"> a. Documented 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 and percent of families referred to and involved in parent-to-parent support program.
<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>	<ul style="list-style-type: none"> a. Number and percent of parents involved in their child's program planning, evaluation, or monitoring. b. Number and percent of parents on the EHDI Advisory Board.

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

<p style="text-align: center;">Program Objectives</p>	<p style="text-align: center;">Performance Indicators</p>
<p>4.1 <i>Risk factors:</i> Each hospital, audiologist and other providers, will identify infants with risk factors for hearing loss and transmit the information to state.</p>	<p>a. Number and 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 infants at risk for late onset and progressive hearing loss.</p>	<p>a. Number and percent of infants with risk factors who are re-screened by 6 months.</p>
<p>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.</p>	<p>a. Number and percent of infants and children identified with acquired hearing loss.</p>

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

Program Objectives	Performance Indicators
<p>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>	<p>a. Number and percent of infant records that include name of the infant's primary care provider. b. Documentation that the results of the infant's audiologic evaluation were sent to their primary care provider.</p>
<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.</p>	<p>a. Documentation in each family plan or IFSP of collaboration between the early intervention systems and the medical home.</p>
<p>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.</p>	<p>a. Documentation that the Resource Guide describing unbiased information regarding early intervention strategies is provided to physicians and other primary care providers.</p>
<p>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>	<p>a. Documentation of plan to provide information on the EHDI program to the Medical Home of each infant and child. b. Number and percent of each type of medical home (physician, midwife, etc.) that receives written information or attends a session about the EHDI Program, or both.</p>
<p>5.5 <i>Parental 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>	<p>a. Number of parents participating in the development and evaluation of the medical home. b. Results of survey or other mechanism to obtain parent feedback</p>
<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>	<p>a. Number and percent of infant records with updated documentation of who the primary care provider is at birth, initial diagnosis, enrollment in early intervention and at each IFSP contact.</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
<p>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 and children who do not pass the screening and interventions for every infant and child from birth through 5 years of age with hearing loss.</p>	<p>a. Written description of computerized system b. Printouts and reports of screening, evaluation, and intervention data.</p>
<p>6.2 <i>Policies and procedures.</i> Each state will have written policies and procedures regarding operation of the EHDI Tracking and Surveillance System.</p>	<p>a. Documentation of policies and procedures manual.</p>
<p>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.</p>	<p>a. Documentation of policy and procedures on informed consent requirements.</p>
<p>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.</p>	<p>a. Number of live-born infants. b. Number and percent of infants screened. c. Documentation of Number and percent of matches with vital records.</p>
<p>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.</p>	<p>a. Number and percent of infants with risk factors. b. Number and type of risk factors for each infant.</p>
<p>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.</p>	<p>a. Report on number and percent of infants screened that includes results for each ear, technology used, and age at screening.</p>

<p>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.</p>	<p>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.</p>
<p>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.</p>	<p>a. Number and percent of infants and children needing follow-up who: -were referred for second screening -missed screening - need a repeat screening -were referred for diagnostics - were referred for early intervention b. Number and percent of infants and children who received follow-up.</p>
<p>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.</p>	<p>a. Written plan to allow case managers and authorized health-care providers to access relevant information.</p>

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

<p>Program Objectives</p>	<p>Performance Indicators</p>
<p>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.</p>	<p>a. List of Advisory Committee members. b. Minutes of Advisory Meetings</p>
<p>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.</p>	<p>a. Annual evaluation reports that include accomplishments of national and state program goals and objectives.</p>
<p>7.3 <i>Feedback from families.</i> The state EHDI program will obtain feedback from parents on the EHDI process</p>	<p>a. Copy of survey of parent concerns and issues. b. Documented results of parent survey to stakeholders.</p>

7.4 *Surveillance of follow-up services.* Each state will ensure that infants and children with hearing loss receive ongoing and appropriate follow-up services.

- a. Number and percent of infants and children with hearing loss that received appropriate ongoing medical services from primary care, otolaryngologists, ophthalmologists, geneticists and genetic counselors.
- b. Number and age of infants and children fitted with implants.
- c. Number and percent of infants and children using each mode of communication, e.g., sign language, oral, cued speech at 6-month intervals.
- d. Number and percent of infants and children achieving communication and social skills scores commensurate with their cognitive abilities age at 1, 3, 5, and 7 years of age.
- e. Number and percent of infants and children with hearing aids that receive follow-up visits at 2-month intervals until age 2 years and 3-month intervals until age 3.