

EHDI Phase II State Model Legislation

An Act establishing statewide tracking, monitoring, and referral of early intervention services provided for infants and children with permanent hearing loss, family support programs, and for other purposes:

Be it enacted by the Senate and General Assembly of the State of _____:

Section 1. Short Title

This Act shall be known as the Early Hearing Detection and Intervention (EHDI) Act.

Section 2. Legislative Findings and Purposes

(A) Findings. The General Assembly finds as follows:

1. Early intervention and treatment of permanent hearing loss in newborns, infants, and children is highly effective in facilitating a child's healthy development in a manner consistent with the child's age and cognitive ability;
2. Universal newborn hearing screening is recognized as the standard of care for all newborns prior to discharge from a hospital or birthing center; however, linkages between hearing screening programs and early intervention programs are not consistently established due to lack of effective and/or underutilized State tracking and monitoring systems;
3. Nationally, almost 52% of infants who do not pass the newborn hearing screening become lost to follow-up or documentation for a variety of reasons, including the lack of effective State EHDI surveillance and tracking systems, inadequate reporting to these systems by providers, and poor communication between State agencies;¹
4. Children who are identified early and enrolled in appropriate early intervention services by six (6) months of age are more likely to demonstrate age-appropriate language development (spoken or signed), cognitive, social, and academic outcomes;²
5. Any degree of hearing loss in one or both ears, when left undetected, can impact a child's speech, language, cognitive and/or social development;³
6. Information regarding hearing loss and intervention opportunities should be communicated to families by qualified early intervention professionals in a culturally competent, language-appropriate, unbiased, and easily understandable format to allow for informed decision-making;⁴
7. Approximately 2.5 million, or 5.4%, of all school-age children, have mild or unilateral hearing loss. Over one-third of these children are projected to fail at least one grade and/or will require additional educational support, costing the educational system over \$5.5 billion.⁵

1 **(B) Purposes. The purpose of this legislation is:**

- 2 1. To provide prompt and effective referral, evaluation, communication, and other developmental
3 support for newborns, infants, and young children identified with hearing loss;
- 4 2. To provide timely access to appropriate family-centered early intervention services for newborns,
5 infants, and children with confirmed hearing loss;
- 6 3. To provide families and caregivers with culturally-competent support programs and access to
7 unbiased information regarding opportunities for early intervention;
- 8 4. To provide the State with the information necessary to effectively plan, establish, and evaluate a
9 comprehensive system of appropriate services for newborns, infants, and children who are at risk
10 of hearing loss, have a hearing loss, or are deaf; and
- 11 5. To develop and monitor the efficacy of diagnostic and early intervention services, including
12 referral to and delivery of information and services by hospitals, diagnostic centers, and early
13 intervention service providers mandated by Part C of the Individuals with Disabilities Education
14 Act (IDEA), 20 USC §§ 1431-1445, as amended by Pub. L. No. 105-17.

15 **Section 3. Definitions**

16 **(A) The following terms used in this act shall have the following meanings unless expressly**
17 **indicated otherwise:**

18 "Child" or "Children" means a child 24 months to nine (9) years of age.

19 "Early intervention" and/or "follow-up care" means the early intervention services described in Part C of
20 IDEA, as well as any necessary hearing and medical services for the diagnosis and management of
21 newborn, infant, or child hearing loss.

22 "Family" or "Families" means a birth parent(s), stepparent(s), adoptive parent(s), legal guardian(s), or
23 other legal custodian of a newborn, infant, or child.

24 "Family Centered" means the beliefs, values, and practices that emphasize the essential role of the
25 family in all aspects of the decision-making and intervention process regarding the young child.

26 "Hearing loss" means a hearing loss of 25dB HL or greater in the frequency region important for speech
27 recognition and comprehension in one or both ears (approximately 500 through 4000 Hz). The definition
28 may be modified by rule to allow for the detection of hearing loss of less than 25dB HL.

29 "Infant(s)" means a child 30 days to 24 months old.

1 "Lead agency" means the government agency or department responsible for the provision of Part C of
2 the Individuals with Disabilities Education Act (IDEA), 20 USC §§ 1431-1445, as amended by Pub. L. No.
3 105-17.

4 "Newborn(s)" means a child up to 29 days old.

5 "Surveillance and Tracking System" means a monitoring and referral system and procedures designed
6 for the collection and transmission of information and data necessary to implement timely and
7 appropriate follow-up of infants identified through hearing screening programs.

8 **Section 4. Surveillance and Tracking System**

9 **(A) The General Assembly recognizes that it is necessary to provide surveillance, tracking, and**
10 **monitoring of newborns, infants, and children identified through newborn hearing screening in**
11 **order to make referrals, render appropriate follow-up care and better establish linkages between**
12 **hearing screening programs, audiological services, and early intervention programs. To facilitate**
13 **the reporting, tracking, and monitoring of newborns, infants, and children who have or are**
14 **suspected to have hearing loss, a State EHDI surveillance and tracking system shall be enhanced**
15 **to track, monitor, and refer newborns, infants, and children through diagnostic and early**
16 **intervention. The system shall be utilized by qualified professionals involved in the detection,**
17 **treatment, diagnosis, and/or referral of newborns or infants with or suspected of having hearing**
18 **loss. The reporting requirements shall be designed to be as simple as possible and easily**
19 **completed by nonprofessional persons when necessary. It is the intent of the General Assembly**
20 **that the surveillance and tracking system, at a minimum, should include the following:**

- 21 1. Service providers such as hospitals, audiologists, and early intervention specialists should be
22 integrated with and provide information to the State EHDI tracking system and any national
23 database or similar system developed by the federal government. It should be designed to
24 interface with electronic health charts, and should be used to measure outcomes and report the
25 effectiveness of services.⁶
- 26 2. Provide the lead agency with the information necessary to effectively plan and develop a system
27 of appropriate early intervention and family support services for newborns, infants, and children
28 with permanent hearing loss and their families.
- 29 3. Provide the appropriate health care professionals with access to information used for referrals
30 and treatment.
- 31 4. Ability to track and monitor newborns, infants, and children identified as at-risk for hearing loss to
32 ensure periodic screening up to nine (9) years of age.

- 1 5. Shared consent forms from parents or guardians to ensure that the implementation of timely
- 2 follow-up and provision of services is not impeded by confidentiality requirements.
- 3 6. A requirement and mechanisms to ensure that timely diagnosis, referrals, and treatment occur.

4 **(B) The information compiled and maintained in the tracking system shall be kept confidential in**
5 **accordance with the applicable requirements and provisions of Part C of IDEA.**

- 6 1. If required by State or federal regulations, written consent of a parent must be obtained before
- 7 any information individually identifying a newborn, infant, or child is released through the tracking
- 8 system.
- 9 2. The tracking system provided under this Act must meet confidentiality requirements in
- 10 accordance with required State and federal privacy guidelines.
- 11 3. Data obtained through or submitted to the tracking system is for the confidential use of the lead
- 12 agency and the persons or public or private entities that the lead agency determines are
- 13 necessary to carry out the functions of the tracking system.
- 14 4. Statistical or aggregated information collected under this section that could not be used to
- 15 individually identify a patient is not confidential.
- 16 5. The lead agency shall work with the State EHDI program to develop written documentation to
- 17 share information among participating programs and define the State EHDI program as a Part C
- 18 participating provider.

19 **(C) The following persons who act in compliance with this section are not civilly or criminally**
20 **liable for furnishing information required by this section: a hospital, clinical laboratory or other**
21 **health care facility, an audiologist, an administrator, officer or employee of a hospital or other**
22 **health care facility, and a physician or employee of a physician.**

23 **Section 5. Provision of Early Intervention Services and Follow-up Care**

24 **(A) The lead agency, or its designee, shall ensure that hearing loss is diagnosed by three (3)**
25 **months of age, or earlier, and infants with confirmed hearing loss receive comprehensive early**
26 **intervention services by six (6) months of age, or earlier.**

- 27 1. The lead agency shall define all children with any degree of diagnosed permanent hearing
- 28 loss as eligible for services under Part C of IDEA by virtue of their diagnosis, regardless of
- 29 whether a measurable delay is present.
- 30 2. Professionals involved in the care and treatment of the newborns, infants, and children must
- 31 document all early intervention, follow-up, and treatment services, including but not limited

1 further diagnoses, recommendations, observations, test results, and referrals, in order to
2 reduce the number of newborns, infants, and children lost to follow-up.

- 3 3. Early intervention services shall be provided by individuals with the knowledge, skills, and
4 experience to address the ongoing assessment, implementation, and evaluation of services
5 that support families and promote child development.
- 6 4. Family-centered services may be provided in a variety of different settings, including the
7 home, school, community centers, daycare center, hospital or clinic, depending on the needs
8 of the child, family, and availability of resources in the community.
- 9 5. Lack of resources may not be the basis for denial of services.

10 **Section 6. Family Resources**

11 **(A) Families shall be provided with unbiased information in a family-centered, culturally**
12 **competent manner and offered the full range of early intervention services and treatment**
13 **options available for hearing loss. Opportunities for early intervention shall be consistent with**
14 **the child's needs, family's goals, and preferences, and be provided in a seamless,**
15 **unambiguous manner to ensure informed transitions through services.**

- 16 1. Appropriate early intervention opportunities may include information regarding amplification
17 options, such as hearing aids or cochlear implants, aural habilitation and communication
18 options (manual language, spoken language, total communication), and family support.

19 **Section 7. Coverage of Services and Devices**

20 **(A) Coverage shall include early intervention services as currently defined under this act, as well**
21 **as devices and prosthetics, including but not limited to amplification devices, hearing aids,**
22 **cochlear implants, ear molds, and assistive listening devices, however characterized or defined**
23 **by the entity providing coverage. These services shall include services provided by a speech-**
24 **language pathologist, audiologist, and/or teacher of the deaf or hard-of-hearing.**

- 25 1. To the extent not federally mandated, the State plan for medical assistance shall include
26 coverage as described in this section.
- 27 2. Each health insurance plan, including self-insured plans, doing business in this State shall
28 provide coverage as described in this section. Co-insurance and co-payments for coverage
29 under this section shall be consistent with other medical services covered under the plan.
- 30 3. Any health insurance plan covering State employees shall include coverage as described in
31 this section.
- 32 4. To the extent services under this section are not covered by Part C of IDEA, the lead agency
33 or its designee shall provide coverage as described in this section.

1 **(B) An entity subject to this section may limit coverage for devices as follows: \$2,000 per hearing**
2 **aid or amplification device per ear every two (2) years; replacement ear molds are covered in full**
3 **up to four (4) times per year for children seven (7) years of age or under; \$2,000 per cochlear**
4 **implant speech processing device every five (5) years.⁷**

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- 6 1. The cost per hearing aid shall be adjusted annually based on the Medicare Economic Index
7 (MEI) or other cost-of-living index established by the State.
 - 8 2. This section does not prohibit an entity subject to this section from providing coverage that is
9 greater or more favorable to an insured or enrolled individual than the coverage required
10 under this section.

11 **(C) The State shall establish a Hearing Aid Loan Bank Program for the purpose of lending hearing**
12 **aids on a temporary basis to the family of an eligible child to ensure that children three (3) years**
13 **of age or under will have maximum auditory input during the critical period of language learning.⁸**

- 14 1. For purposes of this section, an eligible child means a child three (3) years of age or under with
15 documentation of confirmed diagnosis of hearing loss from a referring audiologist, and no
16 immediate access and/or financial means to obtain hearing aids.⁹

17 **(D) An insurer may not limit or exclude services under this section because the services are**
18 **provided under a federal, State, or publicly funded program.**

19 **Section 8. Miscellaneous Provisions**

20 **(A) The lead agency shall promulgate regulations as may be necessary to implement the**
21 **provisions under Sections 4 through 11.**

22 **(B) The Insurance Commissioner shall promulgate regulations necessary to implement the**
23 **provisions under section 7.**

24 **Section 9. Appropriation**

25 **(A) The General Assembly shall make any necessary appropriations to carry out the purposes of**
26 **this act.**

27 **Section 10. Severability**

28 **(A) If any provision or section of this act is held invalid or unconstitutional, the remainder of the**
29 **act shall not be affected.**

1 **Section 11. Effective Date**

2 **(A) This act shall take effect immediately.**

3 **REFERENCES**

¹ Center for Disease Control and Prevention EHDI Hearing Screening and Follow-up Survey (2006).

http://www.cdc.gov/ncbddd/ehdi/documents/EHDI_Summ_2006_Web.pdf.

² Joint Committee on Infant Hearing (JCIH 2007). Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention. Available at www.asha.org/about/legislation-advocacy/federal/ehdi or www.cdc.gov/NCBDDD/ehdi/documents/JCIH_2007.pdf.

³ Danielle S. Ross, PhD., M.Sc. (2006, March/April). Current Trends: Mild and Unilateral Hearing Loss in Children. *Access Audiology*, Vol.5, No.2. Available at <http://www.asha.org/about/legislation-advocacy/federal/ehdi/default.htm>.

⁴ *Ibid.*, at 2.

⁵ Bess, F., Dodd-Murphy, J. & Parker, R. Children with minimal sensorineural hearing loss: Prevalence, educational performance, and functional status. *Ear and Hearing*, 1998; 19(5) 339-354. Approximately 2,484,000 have mild or unilateral hearing loss. Of these, 919,080 (37%) will be projected to fail at least one grade. Assuming an average cost of \$6000 to educate a child for one year, the total expenditure for grade repetition exceeds \$5.5 billion (919,080 x \$6000 = \$5,514,480,000).

⁶ *Ibid.*, at 2.

⁷ Campbell KP, editor. *Investing in Maternal and Child Health: An Employer's Toolkit*. Washington, DC: Center for Prevention and Health Services, National Business Group on Health; 2007; Chapter 2, page 72. Available at www.businessgrouphealth.org/healthtopics/maternalchild/investing.

⁸ As example: Delaware Hearing Aid Loan Bank Re-Authorization Act of 2007. (74 Del. Laws, c. 109, § 1; 76 Del. Laws, c. 129, § 1.) Available at <http://delcode.delaware.gov/title16/c026a/index.shtml>.

⁹ *Ibid.*