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106TH CONGRESS
1ST SESSION

H. R. 1193

To establish programs regarding early detection, diagnosis, and interventions for newborns and infants with hearing loss.

IN THE HOUSE OF REPRESENTATIVES

MARCH 18, 1999

Mr. WALSH (for himself, Mr. BILIRAKIS, Mr. WAXMAN, Mr. DEAL of Georgia, Mr. COBURN, Mr. UPTON, Mr. ACKERMAN, Ms. KILPATRICK, Mrs. KELLY, Mr. SHOWS, Mrs. MORELLA, Mr. MCHUGH, Mr. DUNCAN, Mr. SHERMAN, Mr. MCNULTY, Mr. FROST, Mrs. MALONEY of New York, Mr. BALDACCI, Mr. BERMAN, Mr. WEYGAND, Mr. QUINN, Mr. FRELINGHUYSEN, Mr. KLECZKA, Mr. OLVER, Mr. FOSSELLA, Ms. DELAURO, Mr. GEJDENSON, Mr. LEWIS of Georgia, Mr. YOUNG of Alaska, Mr. PASTOR, Mr. DIXON, Mrs. JOHNSON of Connecticut, Mr. FALEOMAVAEGA, Mr. POMEROY, Ms. ROS-LEHTINEN, Mr. ENGLISH, Mr. FARR of California, Mr. STRICKLAND, Mr. PAYNE, Mr. DOYLE, Ms. SCHAKOWSKY, Mr. WEXLER, Mr. ROTHMAN, Ms. SLAUGHTER, Mrs. CAPPS, and Mr. FOLEY) introduced the following bill; which was referred to the Committee on Commerce

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A BILL

To establish programs regarding early detection, diagnosis, and interventions for newborns and infants with hearing loss.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''Newborn and Infant Hearing Screening and Intervention Act of 1999''.

SEC. 2. EARLY DETECTION, DIAGNOSIS, AND INTERVENTIONS FOR NEWBORNS AND INFANTS WITH HEARING LOSS.

(a) DEFINITIONS.—For the purposes of this Act only, the following terms in this section are defined as follows:

(1) HEARING SCREENING.—Newborn and infant hearing screening consists of objective physiologic procedures to detect possible hearing loss and to identify newborns and infants who, after rescreening, require further audiologic and medical evaluations.

(2) AUDIOLOGIC EVALUATION.—Audiologic evaluation consists of procedures to assess the status of the auditory system; to establish the site of the auditory disorder; the type and degree of hearing loss, and the potential effects of hearing loss on communication; and to identify appropriate treatment and referral options. Referral options should include linkage to state IDEA Part C coordinating agencies or other appropriate agencies, medical evaluation, hearing aid/sensory aid assessment, audiologic rehabilitation treatment, national and

local consumer, self-help, parent, and education organizations, and other family-centered services.

(3) MEDICAL EVALUATION.—Medical evaluation by a physician consists of key components including history, examination, and medical decision making focused on symptomatic and related body systems for the purpose of diagnosing the etiology of hearing loss and related physical conditions, and for identifying appropriate treatment and referral options.

(4) MEDICAL INTERVENTION.—Medical intervention is the process by which a physician provides medical diagnosis and direction for medical and/or surgical treatment options of hearing loss and/or related medical disorder associated with hearing loss.

(5) AUDIOLOGIC REHABILITATION.—Audiologic rehabilitation (intervention) consists of procedures, techniques, and technologies to facilitate the receptive and expressive communication abilities of a child with hearing loss.

(6) EARLY INTERVENTION.—Early intervention (e.g., nonmedical) means providing appropriate services for the child with hearing loss and ensuring that families of the child are provided comprehensive, consumer-oriented information about the full range of family support, training, information services,

communication options and are given the opportunity to consider the full range of educational and program placements and options for their child.

(b) PURPOSES.—The purposes of this Act are to clarify the authority within the Public Health Service Act to authorize statewide newborn and infant hearing screening, evaluation and intervention programs and systems, technical assistance, a national applied research program, and interagency and private sector collaboration for policy development, in order to assist the States in making progress toward the following goals:

(1) All babies born in hospitals in the United States and its territories should have a hearing screening before leaving the birthing facility. Babies born in other countries and residing in the United States via immigration or adoption should have a hearing screening as early as possible.

(2) All babies who are not born in hospitals in the United States and its territories should have a hearing screening within the first 3 months of life.

(3) Appropriate audiologic and medical evaluations should be conducted by 3 months for all newborns and infants suspected of having hearing loss to allow appropriate referral and provisions for

audiologic rehabilitation, medical and early intervention before the age of 6 months.

(4) All newborn and infant hearing screening programs and systems should include a component for audiologic rehabilitation, medical and early intervention options that ensures linkage to any new and existing state-wide systems of intervention and rehabilitative services for newborns and infants with hearing loss.

(5) Public policy in regard to newborn and infant hearing screening and intervention should be based on applied research and the recognition that newborns, infants, toddlers, and children who are deaf or hard-of-hearing have unique language, learning, and communication needs, and should be the result of consultation with pertinent public and private sectors.

(c) STATEWIDE NEWBORN AND INFANT HEARING SCREENING, EVALUATION AND INTERVENTION PROGRAMS AND SYSTEMS.—Under the existing authority of the Public Health Service Act, the Secretary of Health and Human Services (in this Act referred to as the ''Secretary''), acting through the Administrator of the Health Resources and Services Administration, shall make awards of grants or cooperative agreements to develop statewide

newborn and infant hearing screening, evaluation and intervention programs and systems for the following purposes:

(1) To develop and monitor the efficacy of state-wide newborn and infant hearing screening, evaluation and intervention programs and systems. Early intervention includes referral to schools and agencies, including community, consumer, and parent-based agencies and organizations and other programs mandated by Part C of the Individuals with Disabilities Education Act, which offer programs specifically designed to meet the unique language and communication needs of deaf and hard of hearing newborns, infants, toddlers, and children.

(2) To collect data on statewide newborn and infant hearing screening, evaluation and intervention programs and systems that can be used for applied research, program evaluation and policy development.

(d) TECHNICAL ASSISTANCE, DATA MANAGEMENT, AND APPLIED RESEARCH.—

(1) CENTERS FOR DISEASE CONTROL AND PREVENTION.—Under the existing authority of the Public Health Service Act, the Secretary, acting through the Director of the Centers for Disease Control and

Prevention, shall make awards of grants or cooperative agreements to provide technical assistance to State agencies to complement an intramural program and to conduct applied research related to newborn and infant hearing screening, evaluation and intervention programs and systems. The program shall develop standardized procedures for data management and program effectiveness and costs, such as—

(A) to ensure quality monitoring of newborn and infant hearing loss screening, evaluation, and intervention programs and systems;

(B) to provide technical assistance on data collection and management;

(C) to study the costs and effectiveness of newborn and infant hearing screening, evaluation and intervention programs and systems conducted by State-based programs in order to answer issues of importance to state and national policymakers;

(D) to identify the causes and risk factors for congenital hearing loss;

(E) to study the effectiveness of newborn and infant hearing screening, audiologic and medical evaluations and intervention programs

and systems by assessing the health, intellectual and social developmental, cognitive, and language status of these children at school age; and

(F) to promote the sharing of data regarding early hearing loss with state-based birth defects and developmental disabilities monitoring programs for the purpose of identifying previously unknown causes of hearing loss.

(2) NATIONAL INSTITUTES OF HEALTH.—Under the existing authority of the Public Health Service Act, the Director of the National Institutes of Health, acting through the Director of the National Institute on Deafness and Other Communication Disorders, shall for purposes of this section, continue a program of research and development on the efficacy of new screening techniques and technology, including clinical studies of screening methods, studies on efficacy of intervention, and related research.

(e) COORDINATION AND COLLABORATION.—

(1) IN GENERAL.—Under the existing authority of the Public Health Service Act, in carrying out programs under this section, the Administrator of the Health Resources and Services Administration,

the Director of the Centers for Disease Control and Prevention, and the Director of the National Institutes of Health shall collaborate and consult with other Federal agencies; State and local agencies, including those responsible for early intervention services pursuant to Title XIX of the Social Security Act (Medicaid Early and Periodic Screening, Diagnosis and Treatment Program); Title XXI of the Social Security Act (State Children's Health Insurance Program); Title V of the Social Security Act (Maternal and Child Health Block Grant Program; and Part C of the Individuals with Disabilities Education Act); consumer groups of and that serve individuals who are deaf and hard-of-hearing and their families; appropriate national medical and other health and education specialty organizations; persons who are deaf and hard-of-hearing and their families; other qualified professional personnel who are proficient in deaf or hard-of-hearing children's language and who possess the specialized knowledge, skills, and attributes needed to serve deaf and hard-of-hearing newborns, infants, toddlers, children, and their families; third-party payers and managed care organizations; and related commercial industries.

(2) POLICY DEVELOPMENT.—Under the existing authority of the Public Health Service Act, the Administrator of the Health Resources and Services Administration, the Director of the Centers for Disease Control and Prevention, and the Director of the National Institutes of Health shall coordinate and collaborate on recommendations for policy development at the Federal and state levels and with the private sector, including consumer, medical and other health and education professional-based organizations, with respect to newborn and infant hearing screening, evaluation and intervention programs and systems.

(3) STATE EARLY DETECTION, DIAGNOSIS, AND INTERVENTION PROGRAMS AND SYSTEMS; DATA COLLECTION.—Under the existing authority of the Public Health Service Act, the Administrator of the Health Resources and Services Administration and the Director of the Centers for Disease Control and Prevention shall coordinate and collaborate in assisting States to establish newborn and infant hearing screening, evaluation and intervention programs and systems under subsection (c) and to develop a data collection system under subsection (d).

(f) RULE OF CONSTRUCTION.—Nothing in this Act shall be construed to preempt any State law.

(g) AUTHORIZATION OF APPROPRIATIONS.—

(1) STATEWIDE NEWBORN AND INFANT HEARING SCREENING, EVALUATION AND INTERVENTION PROGRAMS AND SYSTEMS.—For the purpose of carrying out subsection (c) under the existing authority of the Public Health Service Act, there are authorized to the Health Resources and Services Administration appropriations in the amount of $5,000,000 for fiscal year 2000, $8,000,000 for fiscal year 2001, and such sums as may be necessary for fiscal year 2002.

(2) TECHNICAL ASSISTANCE, DATA MANAGEMENT, AND APPLIED RESEARCH; CENTERS FOR DISEASE CONTROL AND PREVENTION.—For the purpose of carrying out subsection (d)(1) under the existing authority of the Public Health Service Act, there are authorized to the Centers for Disease Control and Prevention, appropriations in the amount of $5,000,000 for fiscal year 2000, $7,000,000 for fiscal year 2001, and such sums as may be necessary for fiscal year 2002.

(3) TECHNICAL ASSISTANCE, DATA MANAGEMENT, AND APPLIED RESEARCH; NATIONAL INSTI-

TUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS.—For the purpose of carrying out subsection (d)(2) under the existing authority of the Public Health Service Act, there are authorized to the National Institute on Deafness and Other Communication Disorders appropriations for such sums as may be necessary for each of the fiscal years 2000 through 2002.

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