H.R. 1344

To amend the Public Health Service Act to reauthorize a program for early detection, diagnosis, and treatment regarding deaf and hard-of-hearing newborns, infants, and young children.

IN THE HOUSE OF REPRESENTATIVES

MARCH 10, 2015

Mr. GUTHRIE (for himself and Mrs. CAPP) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend the Public Health Service Act to reauthorize a program for early detection, diagnosis, and treatment regarding deaf and hard-of-hearing newborns, infants, and young children.

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 “Early Hearing Detection and Intervention Act of 2015”.

SEC. 2. FINDINGS.

The Congress finds as follows:

(1) Deaf and hard-of-hearing newborns, infants, toddlers, and young children require access to specialized early intervention providers and programs in order to help them meet their linguistic and cognitive potential.

(2) Families of deaf and hard-of-hearing newborns, infants, toddlers, and young children benefit from comprehensive early intervention programs that assist them in supporting their child’s development in all domains.

(3) Best practices principles for early intervention for deaf and hard-of-hearing newborns, infants, toddlers, and young children have been identified in a range of areas including listening and spoken language and visual and signed language acquisition, family-to-family support, support from individuals who are deaf or hard-of-hearing, progress monitoring, and others.

(4) Effective hearing screening and early intervention programs must be in place to identify hearing levels in deaf and hard-of-hearing newborns, infants, toddlers, and young children so that they may access appropriate early intervention programs in a timely manner.
SEC. 3. REAUTHORIZATION OF PROGRAM FOR EARLY DETECTION, DIAGNOSIS, AND TREATMENT REGARDING DEAF AND HARD-OF-HEARING NEWBORNS, INFANTS, AND YOUNG CHILDREN.

Section 399M of the Public Health Service Act (42 U.S.C. 280g–1) is amended to read as follows:

“SEC. 399M. EARLY DETECTION, DIAGNOSIS, AND TREATMENT REGARDING DEAF AND HARD-OF-HEARING NEWBORNS, INFANTS, AND YOUNG CHILDREN.

“(a) HEALTH RESOURCES AND SERVICES ADMINISTRATION.—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, infant, and young childhood hearing screening, diagnosis, evaluation, and intervention programs and systems, and to assist in the recruitment, retention, education, and training of qualified personnel and health care providers for the following purposes:

“(1) To develop and monitor the efficacy of statewide programs and systems for hearing screening of newborns, infants, and young children, prompt evaluation and diagnosis of children referred from screening programs, and appropriate edu-
cational, audiological, and medical interventions for
cchildren confirmed to be deaf or hard-of-hearing,
consistent with the following:

“(A) Early intervention includes referral to
and delivery of information and services by or-
organizations such as schools and agencies (in-
cluding community, consumer, and parent-
based agencies), pediatric medical homes, and
other programs mandated by part C of the In-
dividuals 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, and
young children.

“(B) Information provided to parents must
be accurate, comprehensive, and, where appro-
priate, evidence-based, allowing families to
make important decisions for their child in a
timely way, including decisions relating to all
possible assistive hearing technologies (such as
hearing aids, cochlear implants, and
osseointegrated devices) and communication op-
tions (such as visual and sign language, listen-
ing and spoken language, or both).
“(C) Programs and systems under this paragraph shall offer mechanisms that foster family-to-family and deaf and hard-of-hearing consumer-to-family supports.

“(2) To develop efficient models (both educational and medical) to ensure that newborns, infants, and young children who are identified through hearing screening receive followup by qualified early intervention providers, qualified health care providers, or pediatric medical homes (including by encouraging State agencies to adopt such models).

“(3) To provide for a technical resource center in conjunction with the Maternal and Child Health Bureau of the Health Resources and Services Administration—

“(A) to provide technical support and education for States; and

“(B) to continue development and enhancement of State early hearing detection and intervention programs.

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

“(1) CENTERS FOR DISEASE CONTROL AND PREVENTION.—The Secretary, acting through the Director of the Centers for Disease Control and Pre-
vention, shall make awards of grants or cooperative
agreements to State agencies or their designated en-
tities for development, maintenance, and improve-
ment of data tracking and surveillance systems on
newborn, infant, and young childhood hearing
screenings, audiologic evaluations, medical evalua-
tions, and intervention services; to conduct applied
research related to services and outcomes, and pro-
vide technical assistance related to newborn, infant,
and young childhood hearing screening, evaluation,
and intervention programs, and information systems;
to ensure high-quality monitoring of hearing screen-
ing, evaluation, and intervention programs and sys-
tems for newborns, infants, and young children; and
to coordinate developing standardized procedures for
data management and assessing program and cost
effectiveness. The awards under the preceding sen-
tence may be used—

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

“(B) to study and report on the costs and
effectiveness of newborn, infant, and young
childhood hearing screening, evaluation, diag-
nosis, intervention programs, and systems;
“(C) to collect data and report on newborn, infant, and young childhood hearing screening, evaluation, diagnosis, and intervention programs and systems that can be used—

“(i) for applied research, program evaluation, and policy development; and

“(ii) 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, infant, and young childhood hearing screening, audiologic evaluations, medical evaluations, and intervention programs and systems by assessing the health, intellectual and social developmental, cognitive, and hearing status of these children at school age; and

“(F) to promote the integration, linkage, and interoperability of data regarding early hearing loss and multiple sources to increase information exchanges between clinical care and public health including the ability of States and territories to exchange and share data.

“(2) NATIONAL INSTITUTES OF HEALTH.—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 related to early hearing detection and intervention, including development of technologies and clinical studies of screening methods, efficacy of interventions, and related research.

“(e) COORDINATION AND COLLABORATION.—

“(1) IN GENERAL.—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—

“(A) other Federal agencies;

“(B) State and local agencies, including those responsible for early intervention services pursuant to title XIX of the Social Security Act (42 U.S.C. 1396 et seq.) (Medicaid Early and Periodic Screening, Diagnosis and Treatment Program); title XXI of the Social Security Act (42 U.S.C. 1397aa et seq.) (State Children’s Health Insurance Program); title V of the Social Security Act (42 U.S.C. 701 et seq.) (Ma-
ternal and Child Health Block Grant Program); and part C of the Individuals with Disabilities Education Act (20 U.S.C. 1431 et seq.);

“(C) consumer groups of and that serve individuals who are deaf and hard-of-hearing and their families;

“(D) appropriate national medical and other health and education specialty organizations;

“(E) persons who are deaf and hard-of-hearing and their families;

“(F) 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;

“(G) third-party payers and managed-care organizations; and

“(H) related commercial industries.

“(2) Policy Development.—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 col-
laborate 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, infant, and young childhood hearing screening, evaluation, diagnosis, and intervention programs and systems.

“(3) STATE EARLY DETECTION, DIAGNOSIS, AND INTERVENTION PROGRAMS AND SYSTEMS; DATA COLLECTION.—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——

“(A) to establish newborn, infant, and young childhood hearing screening, evaluation, diagnosis, and intervention programs and systems under subsection (a); and

“(B) to develop a data collection system under subsection (b).

“(d) RULE OF CONSTRUCTION; RELIGIOUS ACCOMMODATION.—Nothing in this section shall be construed to preempt or prohibit any State law, including State laws which do not require the screening for hearing loss of newborns, infants, or young children of parents who object
to the screening on the grounds that such screening conflicts with the parents’ religious beliefs.

“(e) DEFINITIONS.—For purposes of this section:

“(1) The term ‘audiologic’, when used in connection with evaluation, refers to procedures—

“(A) to assess the status of the auditory system;

“(B) 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

“(C) to identify appropriate treatment and referral options, including—

“(i) linkage to State coordinating agencies under part C of the Individuals with Disabilities Education Act (20 U.S.C. 1431 et seq.) or other appropriate agencies;

“(ii) medical evaluation;

“(iii) hearing aid/sensory aid assessment;

“(iv) audiologic rehabilitation treatment; and

“(v) referral to national and local consumer, self-help, parent, and education or-
ganizations, and other family-centered services.

“(2) The term ‘early intervention’ refers to—

“(A) providing appropriate services for the child who is deaf or hard of hearing, including nonmedical services; and

“(B) ensuring the family of the child is—

“(i) provided comprehensive, consumer-oriented information about the full range of family support, training, information services, and language and communication options; and

“(ii) given the opportunity to consider and obtain the full range of such appropriate services, educational and program placements, and other options for their child from highly qualified providers.

“(3) The term ‘medical evaluation’ refers to key components performed by a physician, including history, examination, and medical decisionmaking 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) The term ‘medical intervention’ refers to the process by which a physician provides medical diagnosis and direction for medical or surgical treatment options for hearing loss or related medical disorders.

“(5) The term ‘newborn, infant, and young childhood hearing screening’ refers to objective physiologic procedures to detect possible hearing loss and to identify newborns, infants, and young children who require further audiologic evaluations and medical evaluations.

“(f) AUTHORIZATION OF APPROPRIATIONS.—

“(1) Statewide newborn, infant, and young childhood hearing screening, evaluation and intervention programs and systems.—For the purpose of carrying out subsection (a), there is authorized to be appropriated to the Health Resources and Services Administration $17,800,000 for each of fiscal years 2016 through 2020.

“(2) Technical assistance, data management, and applied research; Centers for Disease Control and Prevention.—For the purpose of carrying out subsection (b)(1), there is authorized to be appropriated to the Centers for Disease Con-
trol and Prevention $10,800,000 for each of fiscal
years 2016 through 2020.

“(3) TECHNICAL ASSISTANCE, DATA MANAGEMENT, AND APPLIED RESEARCH; NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS.—No additional funds are authorized to be appropriated for the purpose of carrying out subsection (b)(2). Such subsection shall be carried out using funds which are otherwise authorized (under section 402A or other provisions of law) to be appropriated for such purpose.”.