

115 TH CONGRESS 1ST SESSION H.R. 1539

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 15, 2017

Mr. Guthrie (for himself and Ms. Matsui) 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.

- 1 Be it enacted by the Senate and House of Representa-
- 2 tives of the United States of America in Congress assembled,
- 3 SECTION 1. SHORT TITLE.
- 4 This Act may be cited as the "Early Hearing Detec-
- 5 tion and Intervention Act of 2017".
- 6 SEC. 2. FINDINGS.
- 7 Congress finds as follows:

- 1 (1) Deaf and hard-of-hearing newborns, infants, 2 and young children require access to specialized 3 early intervention providers and programs in order 4 to help them meet their linguistic and cognitive po-5 tential.
 - (2) Families of deaf and hard-of-hearing newborns, infants, 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, 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, and young children so that they may access appropriate early intervention programs in a timely manner.

1	SEC. 3. REAUTHORIZATION OF PROGRAM FOR EARLY DE-
2	TECTION, DIAGNOSIS, AND TREATMENT RE-
3	GARDING DEAF AND HARD-OF-HEARING
4	NEWBORNS, INFANTS, AND YOUNG CHIL-
5	DREN.
6	Section 399M of the Public Health Service Act (42
7	U.S.C. 280g-1) is amended to read as follows:
8	"SEC. 399M. EARLY DETECTION, DIAGNOSIS, AND TREAT-
9	MENT REGARDING DEAF AND HARD-OF-
10	HEARING NEWBORNS, INFANTS, AND YOUNG
11	CHILDREN.
12	"(a) Health Resources and Services Adminis-
13	TRATION.—The Secretary, acting through the Adminis-
14	trator of the Health Resources and Services Administra-
15	tion, shall make awards of grants or cooperative agree-
16	ments to develop statewide newborn, infant, and young
17	childhood hearing screening, diagnosis, evaluation, and
18	intervention programs and systems, and to assist in the
19	recruitment, retention, education, and training of qualified
20	personnel and health care providers (including education
21	and training of family members) for the following pur-
22	poses:
23	"(1) To develop and monitor the efficacy of
24	statewide programs and systems for hearing screen-
25	ing of newborns, infants, and young children,
26	prompt evaluation and diagnosis of newborns, in-

fants, and young children referred from screening programs, and appropriate educational, audiological, medical, and communications (or language acquisition) interventions (including family support) for newborns, infants, and young children identified as deaf or hard-of-hearing, consistent with the following:

"(A) Early intervention includes referral to, and delivery of, information and services by organizations such as schools and agencies (including community, consumer, and family-based agencies), medical homes for children, and other programs under part C of the Individuals with Disabilities Education Act (20 U.S.C. 1431 et seq.), 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 shall be accurate, comprehensive, and, where appropriate, evidence-based, allowing families to make important decisions for their children in a timely way, including decisions relating to all possible assistive hearing technologies (such as hearing aids, cochlear implants, and

osseointegrated devices) and communication modalities (such as oral and visual communications and language acquisition services and programs).

- "(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 continue to provide technical support to States, through one or more technical resource centers, to assist in further developing and enhancing State early hearing detection and intervention programs.
- "(3) To identify or develop efficient models (educational and medical) to ensure that newborns, infants, and young children who are identified through screening as deaf or hard-of-hearing receive, as appropriate, follow-up by qualified early intervention providers, qualified health care providers, or medical homes for children and referrals to early intervention services (including special education and related services, as appropriate) under part C of the Individuals with Disabilities Education Act (20 U.S.C. 1431 et seq.). State agencies shall be encour-

1	aged to effectively increase the rate of such follow-
2	up and referral.
3	"(b) Technical Assistance, Data Management,
4	AND APPLIED RESEARCH.—
5	"(1) Centers for disease control and
6	PREVENTION.—
7	"(A) IN GENERAL.—The Secretary, acting
8	through the Director of the Centers for Disease
9	Control and Prevention, shall make awards of
10	grants or cooperative agreements to provide
11	technical assistance to State agencies or des-
12	ignated entities of States—
13	"(i) for the development, mainte-
14	nance, and improvement of data tracking
15	and surveillance systems on newborn, in-
16	fant, and young childhood hearing screen-
17	ing, audiologic evaluations, medical evalua-
18	tions, language-acquisition evaluations, and
19	intervention services;
20	"(ii) to conduct applied research re-
21	lated to services and outcomes;
22	"(iii) to provide technical assistance
23	related to newborn, infant, and young
24	childhood hearing screening, evaluation.

1	and intervention programs, and informa-
2	tion systems;
3	"(iv) to ensure high-quality moni-
4	toring of hearing screening, evaluation,
5	and intervention programs and systems for
6	newborns, infants, and young children; and
7	"(v) to coordinate developing stand-
8	ardized procedures for data management
9	and assessing program and cost effective-
10	ness.
11	"(B) USE OF AWARDS.—The awards under
12	subparagraph (A) may be used—
13	"(i) to provide technical assistance on
14	data collection and management;
15	"(ii) to study and report on the costs
16	and effectiveness of newborn, infant, and
17	young childhood hearing screening, evalua-
18	tion, diagnosis, intervention programs, and
19	systems in order to address issues of im-
20	portance to State and national policy mak-
21	ers;
22	"(iii) to collect data and report on
23	newborn, infant, and young childhood
24	hearing screening, evaluation, diagnosis,
25	and intervention programs and systems

1	that can be used for applied research, pro-
2	gram evaluation, and policy development;
3	"(iv) to identify the causes and risk
4	factors for congenital hearing loss;
5	"(v) to study the effectiveness of new-
6	born, infant, and young childhood hearing
7	screening, audiologic evaluations, medical
8	evaluations, and intervention programs and
9	systems by assessing the health, intellec-
10	tual and social developmental, cognitive,
11	and hearing status of children at school
12	age; and
13	"(vi) to promote the integration, link-
14	age, and interoperability of data regarding
15	early hearing loss and multiple sources to
16	increase information exchanges between
17	clinical care and public health, including
18	the ability of States and territories to ex-
19	change and share data.
20	"(2) NATIONAL INSTITUTES OF HEALTH.—The
21	Director of the National Institutes of Health, acting
22	through the Director of the National Institute on
23	Deafness and Other Communication Disorders,
24	shall, for purposes of this section, continue a pro-
25	gram of research and development on the efficacy of

new screening techniques and technology, including clinical studies of screening methods, studies on the efficacy of intervention, and related research.

"(c) 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 agencies responsible for early intervention services (including special education and related services, as appropriate) pursuant to title V of the Social Security Act (42 U.S.C. 701 et seq.) (Maternal and Child Health Services Block Grant), 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), and part C of the Individuals with Disabilities Education Act (20 U.S.C. 1431 et seq.);

1	"(C) consumer groups of, and that serve,
2	individuals who are deaf and hard-of-hearing
3	and their families;
4	"(D) appropriate national medical and
5	other health and education specialty organiza-
6	tions;
7	"(E) individuals who are deaf or hard-of-
8	hearing and their families;
9	"(F) other qualified professional personnel
10	who are proficient in deaf or hard-of-hearing
11	children's language and who possess the special-
12	ized knowledge, skills, and attributes needed to
13	serve deaf and hard-of-hearing newborns, in-
14	fants, young children, and their families;
15	"(G) third-party payers and managed-care
16	organizations; and
17	"(H) related commercial industries.
18	"(2) Policy Development.—The Adminis-
19	trator of the Health Resources and Services Admin-
20	istration, the Director of the Centers for Disease
21	Control and Prevention, and the Director of the Na-
22	tional Institutes of Health shall coordinate and col-
23	laborate on recommendations for policy development
24	at the Federal and State levels and with the private
25	sector, including consumer, medical, and other

- health and education professional-based organizations, with respect to newborn and infant hearing screening, evaluation, diagnosis, and intervention programs and systems.
- 5 "(3) STATE EARLY DETECTION, DIAGNOSIS,
 6 AND INTERVENTION PROGRAMS AND SYSTEMS; DATA
 7 COLLECTION.—The Administrator of the Health Re8 sources and Services Administration and the Direc9 tor of the Centers for Disease Control and Preven10 tion shall coordinate and collaborate in assisting
 11 States—
- "(A) to establish newborn, infant, and young childhood hearing screening, evaluation, diagnosis, and intervention programs and systems under subsection (a); and
- 16 "(B) to develop a data collection system 17 under subsection (b)(1).
- 18 "(d) RULE OF CONSTRUCTION; RELIGIOUS ACCOM-19 MODATION.—Nothing in this section shall be construed to
- 20 preempt or prohibit any State law, including State laws
- 21 that do not require the screening for hearing loss of
- 22 newborns, infants, or young children of any parent who
- 23 objects to the screening on the grounds that such screen-
- 24 ing conflicts with the parent's religious beliefs.
- 25 "(e) Definitions.—For purposes of this section:

1	"(1) The term 'audiologic', when used in con-
2	nection with evaluation, means procedures—
3	"(A) to assess the status of the auditory
4	system;
5	"(B) to establish the site of the auditory
6	disorder, the type and degree of hearing loss,
7	and the potential effects of hearing loss on com-
8	munication; and
9	"(C) to identify appropriate treatment and
10	referral options, including—
11	"(i) linkage to State agencies coordi-
12	nating the programs under part C of the
13	Individuals with Disabilities Education Act
14	(20 U.S.C. 1431 et seq.) or other appro-
15	priate agencies;
16	"(ii) medical evaluation;
17	"(iii) hearing aid or sensory aid as-
18	sessment;
19	"(iv) audiologic rehabilitation treat-
20	ment; and
21	"(v) referral to national and local con-
22	sumer, self-help, family, and education or-
23	ganizations, and other family-centered
24	services.
25	"(2) The term 'early intervention' means—

1	"(A) providing appropriate services for a
2	child who is deaf or hard-of-hearing, including
3	nonmedical services; and
4	"(B) ensuring the family of such child is—
5	"(i) provided comprehensive, con-
6	sumer-oriented information about the full
7	range of family support, training, informa-
8	tion services, and language acquisition in
9	oral and visual modalities; and
10	"(ii) given the opportunity to consider
11	and obtain the full range of such appro-
12	priate services, educational and program
13	placements, and other options for the child
14	from highly qualified providers.
15	"(3) The term 'medical evaluation' means key
16	components performed by a physician, including his-
17	tory, examination, and medical decisionmaking fo-
18	cused on symptomatic and related body systems for
19	the purpose of diagnosing the etiology of hearing
20	loss and related physical conditions, and for identi-
21	fying appropriate treatment and referral options.
22	"(4) The term 'medical intervention' means the
23	process by which a physician provides medical diag-
24	nosis and direction for medical or surgical treatment

- options for hearing loss or other medical disorders associated with hearing loss.
- "(5) The term 'newborn, infant, and young childhood hearing screening' means objective physiologic procedures to detect possible hearing loss and to identify newborns, infants, and young children up to the age of three who require further audiologic evaluations and medical evaluations.

9 "(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 are authorized to be appropriated to the Health Resources and Services Administration \$17,800,000 for each of fiscal years 2018 through 2022.
- "(2) TECHNICAL ASSISTANCE, DATA MANAGE-MENT, AND APPLIED RESEARCH; CENTERS FOR DIS-EASE CONTROL AND PREVENTION.—For the purpose of carrying out subsection (b)(1), there are authorized to be appropriated to the Centers for Disease Control and Prevention \$10,800,000 for each of fiscal years 2018 through 2022.

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"(3) TECHNICAL ASSISTANCE, DATA MANAGE-1 2 MENT, AND APPLIED RESEARCH; NATIONAL INSTI-3 TUTE ON DEAFNESS AND OTHER COMMUNICATION 4 DISORDERS.—No additional funds are authorized to be appropriated for the purpose of carrying out sub-5 6 section (b)(2). Such subsection shall be carried out using funds which are otherwise authorized (under 7 8 section 402A or other provisions of law) to be appro-9 priated for such purpose.".

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