## **COMMITTEE PRINT**

[Showing the text of H.R. 1344 as favorably forwarded by the Subcommittee on Health on July 23, 2015]

114TH CONGRESS 1ST SESSION

- <sup>s</sup> **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. CAPPS) 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 cited as the "Early Hearing Detection
- 5 and Intervention Act of 2015".

 $\mathbf{2}$ 

#### 1 SEC. 2. FINDINGS.

2 The Congress finds as follows:

3 (1) Deaf and hard-of-hearing newborns, infants,
4 toddlers, and young children require access to spe5 cialized early intervention providers and programs in
6 order to help them meet their linguistic and cog7 nitive potential.

8 (2) Families of deaf and hard-of-hearing 9 newborns, infants, toddlers, and young children ben-10 efit from comprehensive early intervention programs 11 that assist them in supporting their child's develop-12 ment in all domains.

13 (3) Best practices principles for early interven-14 tion for deaf and hard-of-hearing newborns, infants, 15 toddlers, and young children have been identified in 16 a range of areas including listening and spoken lan-17 guage and visual and signed language acquisition, 18 family-to-family support, support from individuals 19 who are deaf or hard-of-hearing, progress moni-20 toring, 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.

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-TRATION.—The Secretary, acting through the Adminis-13 trator of the Health Resources and Services Administra-14 tion, shall make awards of grants or cooperative agree-15 16 ments to develop statewide newborn, infant, and young childhood hearing screening, diagnosis, evaluation, and 17 intervention programs and systems, and to assist in the 18 19 recruitment, retention, education, and training of qualified 20 personnel and health care providers for the following pur-21 poses:

"(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
 children confirmed to be deaf or hard-of-hearing,
 consistent with the following:

"(A) Early intervention includes referral to 4 and delivery of information and services by or-5 6 ganizations such as schools and agencies (in-7 cluding community, consumer, and parent-8 based agencies), pediatric medical homes, and 9 other programs mandated by part C of the In-10 dividuals with Disabilities Education Act, which 11 offer programs specifically designed to meet the unique language and communication needs of 12 13 deaf and hard-of-hearing newborns, infants, and 14 young children.

15 "(B) Information provided to parents must 16 be accurate, comprehensive, and, where appro-17 priate, evidence-based, allowing families to 18 make important decisions for their child in a 19 timely way, including decisions relating to all 20 possible assistive hearing technologies (such as 21 hearing aids. cochlear implants, and 22 osseointegrated devices) and communication op-23 tions (such as visual and sign language, listen-24 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 edu-

6 (2) For develop contents models (both edu
6 cational and medical) to ensure that newborns, in7 fants, and young children who are identified through
8 hearing screening receive followup by qualified early
9 intervention providers, qualified health care pro10 viders, or pediatric medical homes (including by en11 couraging 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—

16 "(A) to provide technical support and edu-17 cation for States; and

18 "(B) to continue development and en19 hancement of State early hearing detection and
20 intervention programs.

21 "(b) TECHNICAL ASSISTANCE, DATA MANAGEMENT,
22 AND APPLIED RESEARCH.—

23 "(1) CENTERS FOR DISEASE CONTROL AND
24 PREVENTION.—The Secretary, acting through the
25 Director of the Centers for Disease Control and Pre-

1 vention, shall make awards of grants or cooperative 2 agreements to State agencies or their designated en-3 tities for development, maintenance, and improve-4 ment of data tracking and surveillance systems on 5 newborn, infant, and young childhood hearing 6 screenings, audiologic evaluations, medical evalua-7 tions, and intervention services; to conduct applied 8 research related to services and outcomes, and pro-9 vide technical assistance related to newborn, infant, 10 and young childhood hearing screening, evaluation, 11 and intervention programs, and information systems; 12 to ensure high-quality monitoring of hearing screen-13 ing, evaluation, and intervention programs and sys-14 tems for newborns, infants, and young children; and 15 to coordinate developing standardized procedures for 16 data management and assessing program and cost 17 effectiveness. The awards under the preceding sen-18 tence may be used— 19 "(A) to provide technical assistance on 20 data collection and management;

21 "(B) to study and report on the costs and
22 effectiveness of newborn, infant, and young
23 childhood hearing screening, evaluation, diag24 nosis, intervention programs, and systems;

 $\overline{7}$ 

1	"(C) to collect data and report on new-
2	born, infant, and young childhood hearing
3	screening, evaluation, diagnosis, and interven-
4	tion programs and systems that can be used—
5	"(i) for applied research, program
6	evaluation, and policy development; and
7	"(ii) to answer issues of importance to
8	State and national policymakers;
9	"(D) to identify the causes and risk factors
10	for congenital hearing loss;
11	"(E) to study the effectiveness of newborn,
12	infant, and young childhood hearing screening,
13	audiologic evaluations, medical evaluations, and
14	intervention programs and systems by assessing
15	the health, intellectual and social develop-
16	mental, cognitive, and hearing status of these
17	children at school age; and
18	"(F) to promote the integration, linkage,
19	and interoperability of data regarding early
20	hearing loss and multiple sources to increase in-
21	formation exchanges between clinical care and
22	public health including the ability of States and
23	territories to exchange and share data.
24	"(2) NATIONAL INSTITUTES OF HEALTH.—The
25	Director of the National Institutes of Health, acting

1	through the Director of the National Institute on
2	Deafness and Other Communication Disorders,
3	shall, for purposes of this section, continue a pro-
4	gram of research and development related to early
5	hearing detection and intervention, including devel-
6	opment of technologies and clinical studies of screen-
7	ing methods, efficacy of interventions, and related
8	research.
9	"(c) Coordination and Collaboration.—
10	"(1) IN GENERAL.—In carrying out programs
11	under this section, the Administrator of the Health
12	Resources and Services Administration, the Director
13	of the Centers for Disease Control and Prevention,
14	and the Director of the National Institutes of Health
15	shall collaborate and consult with—
16	"(A) other Federal agencies;
17	"(B) State and local agencies, including
18	those responsible for early intervention services
19	pursuant to title XIX of the Social Security Act
20	(42 U.S.C. 1396 et seq.) (Medicaid Early and
21	Periodic Screening, Diagnosis and Treatment
22	Program); title XXI of the Social Security Act
23	(42 U.S.C. 1397aa et seq.) (State Children's
24	Health Insurance Program); title V of the So-
25	cial Security Act (42 U.S.C. 701 et seq.) (Ma-

1	ternal and Child Health Block Grant Program);
2	and part C of the Individuals with Disabilities
3	Education Act (20 U.S.C. 1431 et seq.);
4	"(C) consumer groups of and that serve in-
5	dividuals who are deaf and hard-of-hearing and
6	their families;
7	"(D) appropriate national medical and
8	other health and education specialty organiza-
9	tions;
10	"(E) persons who are deaf and hard-of-
11	hearing and their families;
12	"(F) other qualified professional personnel
13	who are proficient in deaf or hard-of-hearing
14	children's language and who possess the special-
15	ized knowledge, skills, and attributes needed to
16	serve deaf and hard-of-hearing newborns, in-
17	fants, toddlers, children, and their families;
18	"(G) third-party payers and managed-care
19	organizations; and
20	"(H) related commercial industries.
21	"(2) Policy development.—The Adminis-
22	trator of the Health Resources and Services Admin-
23	istration, the Director of the Centers for Disease
24	Control and Prevention, and the Director of the Na-
25	tional Institutes of Health shall coordinate and col-

1 laborate on recommendations for policy development 2 at the Federal and State levels and with the private 3 sector, including consumer, medical, and other 4 health and education professional-based organiza-5 tions, with respect to newborn, infant, and young 6 childhood hearing screening, evaluation, diagnosis, 7 and intervention programs and systems. 8 "(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—

15 "(A) to establish newborn, infant, and
16 young childhood hearing screening, evaluation,
17 diagnosis, and intervention programs and sys18 tems under subsection (a); and

19 "(B) to develop a data collection system20 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

1	to the screening on the grounds that such screening con-
2	flicts with the parents' religious beliefs.
3	"(e) DEFINITIONS.—For purposes of this section:
4	"(1) The term 'audiologic', when used in con-
5	nection with evaluation, refers to procedures—
6	"(A) to assess the status of the auditory
7	system;
8	"(B) to establish the site of the auditory
9	disorder, the type and degree of hearing loss,
10	and the potential effects of hearing loss on com-
11	munication; and
12	"(C) to identify appropriate treatment and
13	referral options, including—
14	"(i) linkage to State coordinating
15	agencies under part C of the Individuals
16	with Disabilities Education Act (20 U.S.C.
17	1431 et seq.) or other appropriate agen-
18	cies;
19	"(ii) medical evaluation;
20	"(iii) hearing aid/sensory aid assess-
21	ment;
22	"(iv) audiologic rehabilitation treat-
23	ment; and
24	"(v) referral to national and local con-
25	sumer, self-help, parent, and education or-

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

6 "(5) The term 'newborn, infant, and young 7 childhood hearing screening' refers to objective phys-8 iologic procedures to detect possible hearing loss and 9 to identify newborns, infants, and young children 10 who require further audiologic evaluations and med-11 ical evaluations.

12 "(f) Authorization of Appropriations.—

13 ((1))STATEWIDE NEWBORN, INFANT, AND 14 YOUNG CHILDHOOD HEARING SCREENING, EVALUA-15 TION AND INTERVENTION PROGRAMS AND SYS-16 TEMS.—For the purpose of carrying out subsection 17 (a), there is authorized to be appropriated to the 18 Health Resources and Services Administration 19 \$17,800,000 for each of fiscal years 2016 through 20 2020.

21 "(2) TECHNICAL ASSISTANCE, DATA MANAGE22 MENT, AND APPLIED RESEARCH; CENTERS FOR DIS23 EASE CONTROL AND PREVENTION.—For the purpose
24 of carrying out subsection (b)(1), there is authorized
25 to be appropriated to the Centers for Disease Con-

trol and Prevention \$10,800,000 for each of fiscal
 years 2016 through 2020.

3 "(3) TECHNICAL ASSISTANCE, DATA MANAGE-4 MENT, AND APPLIED RESEARCH; NATIONAL INSTI-5 TUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS.—No additional funds are authorized to 6 7 be appropriated for the purpose of carrying out sub-8 section (b)(2). Such subsection shall be carried out 9 using funds which are otherwise authorized (under 10 section 402A or other provisions of law) to be appro-11 priated for such purpose.".