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EARLY HEARING DETECTION AND INTERVENTION ACT OF 2021

DECEMBER 8, 2021.—Committed to the Committee of the Whole House on the State of the Union and ordered to be printed

Mr. PALLONE, from the Committee on Energy and Commerce, submitted the following

R E P O R T

[To accompany H.R. 5561]

The Committee on Energy and Commerce, to whom was referred the bill (H.R. 5561) to reauthorize a program for early detection, diagnosis, and treatment regarding deaf and hard-of-hearing newborns, infants, and young children, and for other purposes, having considered the same, reports favorably thereon with an amendment and recommends that the bill as amended do pass.

CONTENTS

The amendment is as follows:

Strike all after the enacting clause and insert the following:

SECTION 1. SHORT TITLE.

This Act may be cited as the "Early Hearing Detection and Intervention Act of 2021".

SEC. 2. REAUTHORIZATION OF PROGRAM FOR EARLY DETECTION, DIAGNOSIS, AND TREATMENT REGARDING DEAF AND HARD-OF-HEARING NEWBORNS, INFANTS, AND YOUNG CHILDREN.

Section 399M(f) of the Public Health Service Act (42 U.S.C. 280g–1(f)) is amended—

(1) in paragraph (1), by striking "$17,818,000 for fiscal year 2018, $18,173,800 for fiscal year 2019, $18,628,145 for fiscal year 2020, $19,056,592 for fiscal year 2021, and $19,522,758 for fiscal year 2022" and inserting "$17,818,000 for each of fiscal years 2022 through 2026";

(2) in paragraph (2), by striking "$10,800,000 for fiscal year 2018, $11,026,800 for fiscal year 2019, $11,302,470 for fiscal year 2020, $11,562,427 for fiscal year 2021, and $11,851,488 for fiscal year 2022" and inserting "$16,000,000 for each of fiscal years 2022 through 2026"; and

(3) in paragraph (3), by striking "fiscal years 2011 through 2015" and inserting "fiscal years 2022 through 2026".

SEC. 3. GAO STUDY ON STATE EARLY HEARING DETECTION AND INTERVENTION PROGRAMS.

(a) IN GENERAL.—The Comptroller General of the United States shall conduct a study reviewing State early hearing detection and intervention (in this section referred to as "EHDI") programs. Such study shall—

(1) analyze how information collected through such programs informs what is known about EHDI activities to ensure that newborns, infants, and young children have access to timely hearing screenings and early interventions, including information on any disparities in such access;

(2) analyze what is known about how parents use State EHDI websites to seek health and programmatic guidance related to their child's hearing loss diagnosis; and

(3) identify efforts and any promising practices of the Centers for Disease Control and Prevention, the Health Resources and Services Administration, the National Institute on Deafness and Other Communication Disorders, and State EHDI programs—

(A) to address disparities in outreach for, or access to, timely hearing screenings and early interventions; and

(B) to ensure that EHDI follow-up services are communicated and made available to medically underserved populations, including racial and ethnic minorities.

(b) REPORT.—Not later than two years after the date of the enactment of this Act, the Comptroller General shall—

(1) complete the study under subsection (a) and submit a report on the results of the study to—

(A) the Committee on Energy and Commerce of the House of Representatives; and

(B) the Committee on Health, Education, Labor, and Pensions of the Senate; and

(2) make such report publicly available.

I. PURPOSE AND SUMMARY

H.R. 5561 amends the Public Health Service Act to reauthorize early detection, diagnosis, and intervention (EHDI) programs for deaf and hard-of-hearing newborns, infants, and young children at Health Resources and Services Administration (HRSA), the Centers for Disease Control and Prevention (CDC), and the National Institutes for Health (NIH) for fiscal years 2022 through 2026. H.R. 5561 also requires the Comptroller General of the United States (GAO) to conduct a study within two years of enactment on current information on EHDI activities, parent interactions with state EHDI websites, and best practices for addressing disparities in outreach and access to timely hearing screenings and early interventions as well as follow-up services.

II. BACKGROUND AND NEED FOR LEGISLATION

Congenital hearing loss refers to hearing loss that is present at birth.[1] It is the most common birth defect with no currently available cure.[2] According to recent CDC data, the prevalence of congenital hearing loss in 2019 was 1.7 per 1,000 babies screened for hearing loss.[3] Put differently, nearly 6,000 U.S. infants born in 2019 were identified early with permanent hearing loss.[4]

Undetected and untreated hearing loss is linked with academic underachievement, as well as delays in speech, language, social, and emotional development.[5] [6] For this reason, timely diagnosis and treatment is critical to ensuring that all children with hearing loss have the same opportunities to succeed as their hearing peers. Research has found that children whose hearing loss is identified by six months of age have significantly better receptive and expressive skills than children whose hearing loss is identified later.[7] Additionally, children identified for hearing loss that receive treatment within three- to six-months post-birth, respectively, develop better vocabularies than children who are identified and treated for hearing loss at later times.[8]

Hearing loss screening and early intervention were not regular practice in the early 1990s. Prior to 1993, only one in 10 newborns were screened for hearing loss.[9] In 2000, Congress passed and has subsequently reauthorized federal EHDI programs at HRSA, CDC, and NIH.[10] These programs support the development of State and territory programs and systems of care that identify and support children who are deaf or hard of hearing by delivering screening, diagnosis, and early intervention services.[11] EHDI ensures that children who are deaf and hard of hearing are identified at an early age through appropriate newborn, infant, and early childhood screening and receive optimal intervention care to enhance language, literacy, cognitive, social, and emotional development.[12]

Rates of EHDI services have significantly increased in the last 20 years. In 2018, data from CDC reported that 97 percent of all infants were screened prior to one month of age, 77.1 percent of infants received audiological evaluations and diagnoses by three

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[1] American Speech-Language-Hearing Association, *Hearing Loss at Birth (Congenital Hearing Loss*) (https://www.asha.org/public/hearing/congenital-hearing-loss/) (accessed November 30, 2021).

[2] Justine M. Renauld and Martin L. Basch, *Congenital Deafness and Recent Advances Towards Restoring Hearing Loss*, Current Protocols (Mar. 29, 2021) (https://doi.org/10.1002/cpz1.76).

[3] Centers for Disease Control and Prevention, Data and Statistics About Hearing Loss in Children (June 10, 2021) (https://www.cdc.gov/ncbddd/hearingloss/data.html).

[4] *Id.*

[5] *See* Note 4.

[6] Xidong Deng, Marcus Gaffney, and Scott D. Grosse, *Early Hearing Detection and Intervention in the United States: Achievements and Challenges in the 21st Century,* China CDC Weekly (May 22, 2020) (https://doi.org/10.46234/ccdcw2020.097).

[7] *See* Note 3.

[8] Centers for Disease Control and Prevention, *Giving Every Child the Gift of Words* (June 21, 2021) (https://www.cdc.gov/ncbddd/hearingloss/features/feature-vocabulary-hearingloss.html).

[9] Health Resources and Services Administration, *Early Hearing Detection and Intervention* (mchb.hrsa.gov/maternal-child-health-initiatives/early-hearingdetection-and-intervention.html) (accessed October 12, 2021).

[10] Hearing Loss Association of America, Early Hearing and Intervention Act (EHDI) (accessed October 12, 2021) (https://www.hearingloss.org/programs-events/advocacy/know-your-rights/early-hearing-detection-intervention-act-ehdi/).

[11] *See* Note 10.

[12] *See* Note 9.

months of age, and 70.1 percent of infants were enrolled in early intervention services before six months of age.[13]

H.R. 5561 would extend funding for the EHDI programs through fiscal year 2026, ensuring that these services would continue to be available for children that are deaf or hard of hearing.

III. COMMITTEE HEARINGS

For the purposes of section 3(c) of rule XIII of the Rules of the House of Representatives, the following hearing was used to develop or consider H.R. 5561:

The Subcommittee on Health held a legislative hearing on October 20, 2021, entitled "Enhancing Public Health: Legislation to Protect Children and Families." The Subcommittee received testimony from the following witnesses:

- Bruce L. Cassis, D.D.S., M.A.G.D., President, Academy of General Dentistry;
- Raymond DuBois, M.D., Ph.D., Former President, American Association for Cancer Research;
- Donald M. Lloyd-Jones, M.D., Sc.M., President, American Heart Association;
- Ellyn Miller, President and Founder, Smashing Walnuts Foundation; and
- Rick Nolan, Former U.S. Representative of Minnesota.

IV. COMMITTEE CONSIDERATION

Representatives Brett Guthrie (R–KY) and Doris Matsui (D–CA) introduced H.R. 5561, the "Early Hearing Detection and Intervention Act of 2021," on October 12, 2021, and it was referred to the Committee on Energy and Commerce. Subsequently, on October 13, 2021, H.R. 5561 was referred to the Subcommittee on Health. A legislative hearing was held on the bill on October 20, 2021.

On November 4, 2021, the Subcommittee on Health met in open markup session, pursuant to notice, to consider H.R. 5561 and 8 other bills. No amendments were offered during consideration of the bill. Upon conclusion of consideration of the bill, the Subcommittee on Health agreed to report the bill favorably to the full Committee, without amendment, by a voice vote.

On November 17, 2021, the full Committee met in open markup session, pursuant to notice, to consider H.R. 5561 and 11 other bills. During consideration of the bill, an amendment offered by Representative Matsui was agreed to by a voice vote. Upon conclusion of consideration of the bill, the full Committee agreed to a motion on final passage offered by Representative Pallone (D–NJ), Chairman of the Committee, to order H.R. 5561 reported favorably to the House, amended, by a voice vote.

V. COMMITTEE VOTES

Clause 3(b) of rule XIII of the Rules of the House of Representatives requires the Committee to list each record vote on the motion to report legislation and amendments thereto. The Committee advises that there were no record votes taken on H.R. 5561.

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[13] 13 *Id.*

VI. Oversight Findings

Pursuant to clause 3(c)(1) of rule XIII and clause 2(b)(1) of rule X of the Rules of the House of Representatives, the oversight findings and recommendations of the Committee are reflected in the descriptive portion of the report.

VII. New Budget Authority, Entitlement Authority, and Tax Expenditures

Pursuant to 3(c)(2) of rule XIII of the Rules of the House of Representatives, the Committee adopts as its own the estimate of new budget authority, entitlement authority, or tax expenditures or revenues contained in the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974.

The Committee has requested but not received from the Director of the Congressional Budget Office a statement as to whether this bill contains any new budget authority, spending authority, credit authority, or an increase or decrease in revenues or tax expenditures.

VIII. Federal Mandates Statement

The Committee adopts as its own the estimate of Federal mandates prepared by the Director of the Congressional Budget Office pursuant to section 423 of the Unfunded Mandates Reform Act.

IX. Statement of General Performance Goals and Objectives

Pursuant to clause 3(c)(4) of rule XIII, the general performance goal or objective of this legislation is to reauthorize EHDI programs for newborns, infants, and young children.

X. Duplication of Federal Programs

Pursuant to clause 3(c)(5) of rule XIII, no provision of H.R. 5561 is known to be duplicative of another Federal program, including any program that was included in a report to Congress pursuant to section 21 of Public Law 111–139 or the most recent Catalog of Federal Domestic Assistance.

XI. Committee Cost Estimate

Pursuant to clause 3(d)(1) of rule XIII, the Committee adopts as its own the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974.

XII. Earmarks, Limited Tax Benefits, and Limited Tariff Benefits

Pursuant to clause 9(e), 9(f), and 9(g) of rule XXI, the Committee finds that H.R. 5561 contains no earmarks, limited tax benefits, or limited tariff benefits.

XIII. Advisory Committee Statement

No advisory committee within the meaning of section 5(b) of the Federal Advisory Committee Act was created by this legislation.

XIV. Applicability to Legislative Branch

The Committee finds that the legislation does not relate to the terms and conditions of employment or access to public services or accommodations within the meaning of section 102(b)(3) of the Congressional Accountability Act.

XV. Section-by-Section Analysis of the Legislation

Section 1. Short title

Section 1 designates that the Act may be cited as the "Early Hearing Detection and Intervention Act of 2021."

Sec. 2. Reauthorization of program for early detection, diagnosis, and treatment regarding deaf and hard-of-hearing newborns, infants, and young children

Section 2 amends the Public Health Service Act to authorize $17.8 million for programmatic activities at HRSA for each of fiscal years 2022 through 2026 to award grants or cooperative agreements to develop statewide newborn, infant, and young child hearing screening, evaluation, diagnosis, and intervention programs and systems, as well as provide for the recruitment, retention, education, and training of qualified personnel to conduct such activities.

Section 2 also authorizes $16 million for programmatic activities at CDC for each of fiscal years 2022 through 2026 for grants or cooperative agreements to provide technical assistance to State agencies or designated entities of States related to hearing screening, evaluation, diagnosis, and intervention services.

In addition, Section 2 authorizes such sums as necessary for programmatic activities at the National Institute on Deafness and Other Communication Diseases for each of fiscal years 2022 through 2026 for research and development on the efficacy of new screening techniques, technology, and intervention, including clinical studies of screening methods and other related research.

Sec. 3. GAO study on State Early Hearing Detection and Intervention programs

Section 3 requires GAO to conduct a study reviewing State EHDI programs. This study shall (1) analyze how information collected through State EHDI programs informs what is known about EHDI activities to ensure newborns, infants, and young children have access to timely hearing screenings and early interventions, including information on any disparities in such access; (2) analyze parent use of State EHDI websites when seeking health and programmatic guidance related to their child's hearing loss diagnosis; and (3) identify efforts and best practices of CDC, HRSA, and the National Institute on Deafness and Other Communication Disorders, and State EHDI programs to address disparities in outreach for or access to timely hearing screenings and early intervention as well as follow-up services. GAO shall complete the study and issue a report to the House Committee on Energy and Commerce and the Senate Committee on Health, Education, Labor, and Pensions within two years of enactment.

XVI. CHANGES IN EXISTING LAW MADE BY THE BILL, AS REPORTED

In compliance with clause 3(e) of rule XIII of the Rules of the House of Representatives, changes in existing law made by the bill, as reported, are shown as follows (existing law proposed to be omitted is enclosed in black brackets, new matter is printed in italics, and existing law in which no change is proposed is shown in roman):

PUBLIC HEALTH SERVICE ACT

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TITLE III—GENERAL POWERS AND DUTIES OF PUBLIC HEALTH SERVICE

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PART P—ADDITIONAL PROGRAMS

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

(a) STATEWIDE NEWBORN, INFANT, AND YOUNG CHILD HEARING SCREENING, EVALUATION AND INTERVENTION PROGRAMS AND SYSTEMS.—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 child hearing screening, evaluation, diagnosis, and intervention programs and systems, and to assist in the recruitment, retention, education, and training of qualified personnel and health care providers (including, as appropriate, education and training of family members), 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 (referred to in this section as "children"); prompt evaluation and diagnosis of children referred from screening programs; and appropriate educational, audiological, medical, and communication (or language acquisition) interventions (including family support), for 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), in health care settings (including medical homes for children), and in 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 children.

(B) Information provided to families should be accurate, comprehensive, up-to-date, and evidence-based, as appropriate, to allow families to make important decisions for their children in a timely manner, including decisions with

respect to the full range of assistive hearing technologies and communications modalities, as appropriate.

(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 children who are identified as deaf or hard-of-hearing through screening receive follow-up by qualified early intervention providers or qualified health care providers (including those at medical homes for children), and referrals, as appropriate, including to early intervention services under part C of the Individuals with Disabilities Education Act. State agencies shall be encouraged to effectively increase the rate of such follow-up and referral.

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

(1) CENTERS FOR DISEASE CONTROL AND PREVENTION.—

(A) IN GENERAL.—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 or designated entities of States—

(i) to develop, maintain, and improve data collection systems related to newborn, infant, and young child hearing screening, evaluation (including audiologic, medical, and language acquisition evaluations), diagnosis, and intervention services;

(ii) to conduct applied research related to newborn, infant, and young child hearing screening, evaluation, and intervention programs and outcomes;

(iii) to ensure quality monitoring of hearing screening, evaluation, and intervention programs and systems for newborns, infants, and young children; and

(iv) to support newborn, infant, and young child hearing screening, evaluation, and intervention programs, and information systems.

(B) USE OF AWARDS.—The awards made under subparagraph (A) may be used—

(i) to provide technical assistance on data collection and management, including to coordinate and develop standardized procedures for data management;

(ii) to assess and report on the cost and program effectiveness of newborn, infant, and young child hearing screening, evaluation, and intervention programs and systems;

(iii) to collect data and report on newborn, infant, and young child hearing screening, evaluation, diagnosis, and intervention programs and systems for applied research, program evaluation, and policy improvement;

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

(v) to study the effectiveness of newborn, infant, and young child hearing screening, audiologic and 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

(vi) to promote the integration and interoperability of data regarding early hearing loss across multiple sources to increase the flow of information between clinical care and public health settings, 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 on the efficacy of new screening techniques and technology, including clinical studies of screening methods, studies on 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 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;

(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) individuals who are deaf or 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 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 and infant 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 child 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 that do not require the screening for hearing loss of children of parents who object to the screening on the grounds that such screening conflicts with the parent's religious beliefs.

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

(1) The term "audiologic", when used in connection with evaluation, means 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 or other appropriate agencies;

(ii) medical evaluation;

(iii) assessment for the full range of assistivehearing technologies appropriate for newborns, infants, and young children;

(iv) audiologic rehabilitation treatment; and

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

(2) The term "early intervention"means—

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

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

(i) provided comprehensive, consumer-oriented information about the full range of family support, training, information services, and language acquisition in oral and visual modalities; and

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

(3) The term "medical evaluation"means key components performed by a physician 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) The term "medical intervention"means the process by which a physician provides medical diagnosis 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 child hearing screening" means objective physiologic procedures to detect possible hearing loss and to identify newborns, infants, and young children under 3 years of age who require further audiologic and medical evaluations.

(f) AUTHORIZATION OF APPROPRIATIONS.—

(1) STATEWIDE NEWBORN AND INFANT 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 **[**$17,818,000 for fiscal year 2018, $18,173,800 for fiscal year 2019, $18,628,145 for fiscal year 2020, $19,056,592 for fiscal year 2021, and $19,522,758 for fiscal year 2022**]** *$17,818,000 for each of fiscal years 2022 through 2026*.

(2) TECHNICAL ASSISTANCE, DATA MANAGEMENT, AND APPLIED RESEARCH; CENTERS FOR DISEASE 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 fiscal year 2018, $11,026,800 for fiscal year 2019, $11,302,470 for fiscal year 2020, $11,562,427 for fiscal year 2021, and $11,851,488 for fiscal year 2022**]** *$16,000,000 for each of fiscal years 2022 through 2026*.

(3) TECHNICAL ASSISTANCE, DATA MANAGEMENT, AND APPLIED RESEARCH; NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS.—For the purpose of carrying out subsection (b)(2), there are authorized to be appropriated to the National Institute on Deafness and Other Communication Disorders such sums as may be necessary for **[**fiscal years 2011 through 2015**]** *fiscal years 2022 through 2026*.

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