

IMPROVING THE HEALTH OF CHILDREN ACT

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. 5551]

The Committee on Energy and Commerce, to whom was referred the bill (H.R. 5551) to amend title III of the Public Health Service Act to reauthorize the National Center on Birth Defects and Developmental Disabilities, and for other purposes, having considered the same, reports favorably thereon with an amendment and recommends that the bill as amended do pass.

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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 “Improving the Health of Children Act”.

SEC. 2. REAUTHORIZATION OF THE NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES.

Section 317C of the Public Health Service Act (42 U.S.C. 247b–4) is amended—

(1) by striking subsection (a)(4) and inserting the following:

“(4) **SPECIFIC PROGRAMS.**—The Secretary, acting through the Director of the Center, shall continue to carry out programs related to—

- “(A) early identification of developmental delay and disability;
- “(B) birth defects;
- “(C) folic acid;
- “(D) cerebral palsy;
- “(E) intellectual disabilities;
- “(F) child development;
- “(G) newborn screening;
- “(H) autism;
- “(I) fragile X syndrome;
- “(J) fetal alcohol spectrum disorders and other conditions related to pre-natal substance use;
- “(K) pediatric genetic disorders;
- “(L) neuromuscular diseases;
- “(M) congenital heart defects;
- “(N) attention-deficit/hyperactivity disorder;
- “(O) stillbirth;
- “(P) Tourette Syndrome; or
- “(Q) any other relevant disease, disability, disorder, or condition, as determined the Secretary.”;

(2) in subsection (c), in the matter preceding paragraph (1), by striking “Not later than February 1” and all that follows through “2 fiscal years—” and inserting the following: “The Secretary shall submit biennially to the Committee on Energy and Commerce of the House of Representatives, and the Committee on Health, Education, Labor, and Pensions of the Senate, a report that—”;

(3) in subsection (f), by striking “such sums as may be necessary for each of fiscal years 2003 through 2007” and inserting “\$186,010,000 for each of fiscal years 2022 through 2026”.

SEC. 3. EFFECTS OF FOLIC ACID IN PREVENTION OF BIRTH DEFECTS.

Section 317J of the Public Health Service Act (42 U.S.C. 247b–11) is amended by striking subsection (e) (relating to authorization of appropriations).

I. PURPOSE AND SUMMARY

H.R. 5551, the “Improving the Health of Children Act,” reauthorizes the National Center for Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC) for fiscal years 2022 through 2026. The legislation would authorize CDC to carry out programs related to birth defects, folic acid, cerebral palsy, intellectual disabilities, child development, newborn screening, autism, fragile X syndrome, fetal alcohol syndrome, Tourette syndrome, pediatric genetic disorders, disability prevention, or other relevant diseases. The legislation authorizes \$186,010,000 for these activities each of fiscal years 2022 through 2026.

II. BACKGROUND AND NEED FOR LEGISLATION

Every four and one-half minutes, a baby is born with a birth defect in the United States with nearly 1 in 33 babies affected by birth defects each year.¹ Birth defects are structural changes present at birth that can affect almost any part or parts of the body (e.g., heart, brain, or foot). Birth defects can vary from mild to severe, which can affect the expected lifespan of a person with a birth

¹Centers for Disease Control and Prevention. Update on Overall Prevalence of Major Birth Defects—Atlanta, Georgia, 1978–2005. MMWR Morb Mortal Wkly Rep. 2008;57(1):1–5.

defect.² Developmental disabilities include limitations in function resulting from disorders of the developing nervous system.³ These limitations manifest during infancy or childhood as delays in reaching developmental milestones or as lack of function in one or multiple areas, including cognition, motor performance, vision, hearing, speech, and behavior.⁴

The National Center on Birth Defects and Developmental Disabilities (NCBDDD) within CDC was established in April 2001 as a result of the enactment of the Children’s Health Act of 2000 (P.L. 106–310).⁵ The impetus for the establishment of the NCBDDD was a desire to focus public health work on enhanced research into the causes of birth defects and developmental disabilities; to help children to develop and reach their full potential; and to promote the health and well-being among people of all ages with disabilities, including blood disorders.⁶

While the center has continued to consistently receive appropriations from Congress, this legislation reauthorizes NCBDDD for the first time in 15 years. The legislation reinforces NCBDDD’s core mission and authorizes an increase in funding that will enable the Center to continue to carry out more than a dozen infant and child health programs.⁷ The legislation is needed to continue to make critical investments to support the public health surveillance and research programs at NCBDDD, which are relied upon for information used to identify causes of birth defects, research opportunities, and improve the health of those living with birth defects or disabilities. The NCBDDD partners with states, academic centers, health care providers, and other external partners through numerous programs to advance their mission.⁸

III. COMMITTEE HEARINGS

For the purposes of section 3(c) of rule XIII of the Rules of the House of Representatives, the following hearing[s] was [were] used to develop or consider H.R. 5551:

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;

²March of Dimes, *Birth Defects & Other Health Conditions* (<https://www.marchofdimers.org/complications/birth-defects-other-health-conditions.aspx>).

³Institute of Medicine (US) Committee on Nervous System Disorders in Developing Countries. *Neurological, Psychiatric, and Developmental Disorders: Meeting the Challenge in the Developing World* (2001) (<https://www.ncbi.nlm.nih.gov/books/NBK223473/>).

⁴*Id.*

⁵National Center on Birth Defects and Developmental Disabilities, *Our History* (<https://www.cdc.gov/ncbddd/aboutus/timeline/index.html>).

⁶Friends of NCBDDD, *About Us* (<https://friendsofncbddd.org/about-us/>).

⁷National Center on Birth Defects and Developmental Disabilities, *Fiscal Year 2020 Budget* (<https://www.cdc.gov/ncbddd/aboutus/budget/index.html>).

⁸Friends of NCBDDD, *NCBDDD State Fact Sheets* (<https://friendsofncbddd.org/ncbddd-state-fact-sheets/>).

- * Elyn Miller, President and Founder, Smashing Walnuts Foundation;
- * Rick Nolan, Former U.S. Representative (MN);
- * Jenny Radesky, M.D., Assistant Professor of Pediatrics, University of Michigan Medical School; and
- * Stacey Stewart, President and CEO, March of Dimes.

IV. COMMITTEE CONSIDERATION

Representatives Earl L. “Buddy” Carter (R-GA), Henry Cuellar (D-TX), Lori Trahan (D-MA), G.K. Butterfield (D-NC), and Richard Hudson (R-NC) introduced H.R. 5551, the “Improving the Health of Children Act,” on October 12, 2021, and it was referred to the Committee on Energy and Commerce. Subsequently, on October 13, 2021, H.R. 5551 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. 5551 and 8 other bills. During consideration of the bill, an amendment in the nature of a substitute (AINS) offered by Representative Carter was agreed to by a voice vote. Upon conclusion of consideration of the bill, the Subcommittee on Health agreed to report the bill favorably to the full Committee, amended, by a voice vote.

On November 17, 2021, the full Committee met in open markup session, pursuant to notice, to consider H.R. 5551 and 11 other bills. No amendments were offered during consideration of the bill. 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. 5551 reported favorably to the House, as 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. 5551.

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 provide a five-year reauthorization of the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention.

X. DUPLICATION OF FEDERAL PROGRAMS

Pursuant to clause 3(c)(5) of rule XIII, no provision of H.R. 5551 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. 5551 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 short title may be cited as the “Improving the Health of Children Act.”

Sec. 2. Reauthorization of the National Center on Birth Defects and Developmental Disabilities

Section 2 amends the Public Health Service Act (PHSA) to update the specific programs at the NCBDDD that the Secretary of Health and Human Services, acting through the Director of CDC, shall carry out, to include: early identification of developmental delay and disability; birth defects; folic acid; cerebral palsy; intellectual disabilities; child development; newborn screening; autism; fragile X syndrome; fetal alcohol spectrum disorders and other conditions related to prenatal substance use; pediatric genetic disorders; neuromuscular diseases; congenital heart defects; attention-deficit/hyperactivity disorder; stillbirth; Tourette Syndrome; or any other relevant disease, disability, disorder, or condition, as determined by the Secretary.

Section 2 also updates the biennially required report requirement by the Secretary of HHS to the Committee on Energy and Commerce of the House of Representatives and the Committee on Health, Education, Labor, and Pensions of the Senate.

Section 2 further amends the authorization level for the activities of the NCBDDD to be \$186,010,000 for each of fiscal years 2022 through 2026.

Sec. 3. Effects of folic acid in prevention of birth defects

Section 3 amends the PHSA by striking the specific authorization of appropriations for folic acid research and prevention.

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

* * * * *

TITLE III—GENERAL POWERS AND DUTIES OF PUBLIC HEALTH SERVICE

* * * * *

PART B—FEDERAL-STATE COOPERATION

* * * * *

NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES

SEC. 317C. (a) IN GENERAL.—

(1) NATIONAL CENTER.—There is established within the Centers for Disease Control and Prevention a center to be known as the National Center on Birth Defects and Developmental Disabilities (referred to in this section as the “Center”), which

shall be headed by a director appointed by the Director of the Centers for Disease Control and Prevention.

(2) GENERAL DUTIES.—The Secretary shall carry out programs—

(A) to collect, analyze, and make available data on birth defects, developmental disabilities, and disabilities and health (in a manner that facilitates compliance with subsection (c)(2)), including data on the causes of such defects and disabilities and on the incidence and prevalence of such defects and disabilities;

(B) to operate regional centers for the conduct of applied epidemiological research on the prevention of such defects and disabilities;

(C) to provide information and education to the public on the prevention of such defects and disabilities;

(D) to conduct research on and to promote the prevention of such defects and disabilities, and secondary health conditions among individuals with disabilities; and

(E) to support a National Spina Bifida Program to prevent and reduce suffering from the Nation's most common permanently disabling birth defect.

(3) FOLIC ACID.—The Secretary shall carry out section 317J through the Center.

[(4) CERTAIN PROGRAMS.—

[(A) TRANSFERS.—All programs and functions described in subparagraph (B) are transferred to the Center, effective upon the expiration of the 180-day period beginning on the date of the enactment of the Children's Health Act of 2000.

[(B) RELEVANT PROGRAMS.—The programs and functions described in this subparagraph are all programs and functions that—

[(i) relate to birth defects; folic acid; cerebral palsy; intellectual disabilities; child development; newborn screening; autism; fragile X syndrome; fetal alcohol syndrome; pediatric genetic disorders; disability prevention; or other relevant diseases, disorders, or conditions as determined the Secretary; and

[(ii) were carried out through the National Center for Environmental Health as of the day before the date of the enactment of the Act referred to in subparagraph (A).

[(C) RELATED TRANSFERS.—Personnel employed in connection with the programs and functions specified in subparagraph (B), and amounts available for carrying out the programs and functions, are transferred to the Center, effective upon the expiration of the 180-day period beginning on the date of the enactment of the Act referred to in subparagraph (A). Such transfer of amounts does not affect the period of availability of the amounts, or the availability of the amounts with respect to the purposes for which the amounts may be expended.]

(4) SPECIFIC PROGRAMS.—*The Secretary, acting through the Director of the Center, shall continue to carry out programs related to—*

- (A) *early identification of developmental delay and disability;*
- (B) *birth defects;*
- (C) *folic acid;*
- (D) *cerebral palsy;*
- (E) *intellectual disabilities;*
- (F) *child development;*
- (G) *newborn screening;*
- (H) *autism;*
- (I) *fragile X syndrome;*
- (J) *fetal alcohol spectrum disorders and other conditions related to prenatal substance use;*
- (K) *pediatric genetic disorders;*
- (L) *neuromuscular diseases;*
- (M) *congenital heart defects;*
- (N) *attention-deficit/hyperactivity disorder;*
- (O) *stillbirth;*
- (P) *Tourette Syndrome; or*
- (Q) *any other relevant disease, disability, disorder, or condition, as determined the Secretary.*

(b) GRANTS AND CONTRACTS.—

(1) IN GENERAL.—In carrying out subsection (a), the Secretary may make grants to and enter into contracts with public and nonprofit private entities.

(2) SUPPLIES AND SERVICES IN LIEU OF AWARD FUNDS.—

(A) Upon the request of a recipient of an award of a grant or contract under paragraph (1), the Secretary may, subject to subparagraph (B), provide supplies, equipment, and services for the purpose of aiding the recipient in carrying out the purposes for which the award is made and, for such purposes, may detail to the recipient any officer or employee of the Department of Health and Human Services.

(B) With respect to a request described in subparagraph (A), the Secretary shall reduce the amount of payments under the award involved by an amount equal to the costs of detailing personnel and the fair market value of any supplies, equipment, or services provided by the Secretary. The Secretary shall, for the payment of expenses incurred in complying with such request, expend the amounts withheld.

(3) APPLICATION FOR AWARD.—The Secretary may make an award of a grant or contract under paragraph (1) only if an application for the award is submitted to the Secretary and the application is in such form, is made in such manner, and contains such agreements, assurances, and information as the Secretary determines to be necessary to carry out the purposes for which the award is to be made.

(c) BIENNIAL REPORT.—[Not later than February 1 of fiscal year 1999 and of every second such year thereafter, the Secretary shall submit to the Committee on Commerce of the House of Representatives, and the Committee on Labor and Human Resources of the Senate, a report that, with respect to the preceding 2 fiscal years—
] *The Secretary shall submit biennially to the Committee on Energy and Commerce of the House of Representatives, and the Committee*

on Health, Education, Labor, and Pensions of the Senate, a report that—

(1) contains information regarding the incidence and prevalence of birth defects, developmental disabilities, and the health status of individuals with disabilities and the extent to which these conditions have contributed to the incidence and prevalence of infant mortality and affected quality of life;

(2) contains information under paragraph (1) that is specific to various racial and ethnic groups (including Hispanics, non-Hispanic whites, Blacks, Native Americans, and Asian Americans);

(3) contains an assessment of the extent to which various approaches of preventing birth defects, developmental disabilities, and secondary health conditions among individuals with disabilities have been effective;

(4) describes the activities carried out under this section;

(5) contains information on the incidence and prevalence of individuals living with birth defects and disabilities or developmental disabilities, information on the health status of individuals with disabilities, information on any health disparities experienced by such individuals, and recommendations for improving the health and wellness and quality of life of such individuals;

(6) contains a summary of recommendations from all birth defects research conferences sponsored by the Centers for Disease Control and Prevention, including conferences related to spina bifida; and

(7) contains any recommendations of the Secretary regarding this section.

(d) **APPLICABILITY OF PRIVACY LAWS.**—The provisions of this section shall be subject to the requirements of section 552a of title 5, United States Code. All Federal laws relating to the privacy of information shall apply to the data and information that is collected under this section.

(e) **ADVISORY COMMITTEE.**—Notwithstanding any other provision of law, the members of the advisory committee appointed by the Director of the National Center for Environmental Health that have expertise in birth defects, developmental disabilities, and disabilities and health shall be transferred to and shall advise the National Center on Birth Defects and Developmental Disabilities effective on the date of enactment of the Birth Defects and Developmental Disabilities Prevention Act of 2003.

(f) **AUTHORIZATION OF APPROPRIATIONS.**—For the purpose of carrying out this section, there are authorized to be appropriated **[such sums as may be necessary for each of fiscal years 2003 through 2007]** *\$186,010,000 for each of fiscal years 2022 through 2026.*

* * * * *

EFFECTS OF FOLIC ACID IN PREVENTION OF BIRTH DEFECTS

SEC. 317J. (a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall expand and intensify programs (directly or through grants or contracts) for the following purposes:

(1) To provide education and training for health professionals and the general public for purposes of explaining the effects of folic acid in preventing birth defects and for purposes of encouraging each woman of reproductive capacity (whether or not planning a pregnancy) to consume on a daily basis a dietary supplement that provides an appropriate level of folic acid.

(2) To conduct research with respect to such education and training, including identifying effective strategies for increasing the rate of consumption of folic acid by women of reproductive capacity.

(3) To conduct research to increase the understanding of the effects of folic acid in preventing birth defects, including understanding with respect to cleft lip, cleft palate, and heart defects.

(4) To provide for appropriate epidemiological activities regarding folic acid and birth defects, including epidemiological activities regarding neural tube defects.

(b) CONSULTATIONS WITH STATES AND PRIVATE ENTITIES.—In carrying out subsection (a), the Secretary shall consult with the States and with other appropriate public or private entities, including national nonprofit private organizations, health professionals, and providers of health insurance and health plans.

(c) TECHNICAL ASSISTANCE.—The Secretary may (directly or through grants or contracts) provide technical assistance to public and nonprofit private entities in carrying out the activities described in subsection (a).

(d) EVALUATIONS.—The Secretary shall (directly or through grants or contracts) provide for the evaluation of activities under subsection (a) in order to determine the extent to which such activities have been effective in carrying out the purposes of the program under such subsection, including the effects on various demographic populations. Methods of evaluation under the preceding sentence may include surveys of knowledge and attitudes on the consumption of folic acid and on blood folate levels. Such methods may include complete and timely monitoring of infants who are born with neural tube defects.

[(e) AUTHORIZATION OF APPROPRIATIONS.—For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2001 through 2005.]

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