

BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES PREVENTION ACT OF 2003

FEBRUARY 13, 2003.—Committed to the Committee of the Whole House on the State of the Union and ordered to be printed

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

R E P O R T

[To accompany H.R. 398]

[Including cost estimate of the Congressional Budget Office]

The Committee on Energy and Commerce, to whom was referred the bill (H.R. 398) to revise and extend the Birth Defects Prevention Act of 1998, having considered the same, report favorably thereon with a technical amendment and recommend that the bill as amended do pass.

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The amendment (stated in terms of the page and line number of the introduced bill) is as follows:

Page 4, line 9, insert “at the end of the second sentence” after “before the period”.

PURPOSE AND SUMMARY

H.R. 398, the Birth Defects and Developmental Disabilities Act, reauthorizes the National Center on Birth Defects and Disabilities at the Centers for Disease Control and Prevention (CDC) and expands its programmatic activities. The legislation also amends the Developmental Disabilities Act with regard to the funding of state developmental disabilities councils.

BACKGROUND AND NEED FOR LEGISLATION

Birth defects are the leading cause of infant mortality in the United States, accounting for more than 20% of all infant deaths. Of about 120,000 U.S. babies born each year with a birth defect, 8,000 die during their first year of life. In addition, birth defects are the fifth-leading cause of years of potential life lost and contribute substantially to childhood morbidity and long-term disability. Tragically, the causes of about 70% of all birth defects are unknown.

Developmental disabilities are a diverse group of physical, cognitive, psychological, sensory, and speech impairments that begin anytime during development up to 18 years of age. Approximately 2% of school-aged children in the United States have a serious developmental disability. Like birth defects, in most instances, the cause of the disability is not known.

In 1998, Congress passed the Birth Defects Prevention Act (P.L. 105-168) to authorize the CDC to provide surveillance, research, and services aimed at prevention of birth defects and developmental disabilities. Authorization of appropriations for the National Center for Birth Defects and Developmental Disabilities expired in fiscal year 2002.

HEARINGS

The Committee on Energy and Commerce has not held hearings on the legislation.

COMMITTEE CONSIDERATION

On Wednesday, January 29, 2003, the Full Committee on Energy and Commerce met in open markup session and ordered H.R. 398 favorably reported to the House, without amendment, by a voice vote, a quorum being present.

COMMITTEE VOTES

There were no record votes taken in connection with ordering H.R. 398 reported. A motion by Mr. Tauzin to order H.R. 398 reported to the House, without amendment, was agreed to by a voice vote.

COMMITTEE OVERSIGHT FINDINGS

Pursuant to clause 3(c)(1) of rule XIII of the Rules of the House of Representatives, the Committee has not held oversight or legislative hearings on this legislation.

STATEMENT OF GENERAL PERFORMANCE GOALS AND OBJECTIVES

The goal of H.R. 398, the Birth Defects and Developmental Disabilities Act of 2003 is to reauthorize the programmatic activities at the National Center on Birth Defects and Disabilities at the Centers for Disease Control and Prevention.

NEW BUDGET AUTHORITY, ENTITLEMENT AUTHORITY, AND TAX EXPENDITURES

In compliance with clause 3(c)(2) of rule XIII of the Rules of the House of Representatives, the Committee finds that H.R. 398, the "Birth Defects and Developmental Disabilities Prevention Act of 2003", would result in no new or increased budget authority, entitlement authority, or tax expenditures or revenues.

COMMITTEE COST ESTIMATE

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.

CONGRESSIONAL BUDGET OFFICE ESTIMATE

Pursuant to clause 3(c)(3) of rule XIII of the Rules of the House of Representatives, the following is the cost estimate provided by the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974:

U.S. CONGRESS,
CONGRESSIONAL BUDGET OFFICE,
Washington, DC, February 11, 2003.

Hon. W.J. "BILLY" TAUZIN,
*Chairman, Committee on Energy and Commerce,
House of Representatives, Washington, DC.*

DEAR MR. CHAIRMAN: The Congressional Budget Office has prepared the enclosed cost estimate for H.R. 398, the Birth Defects and Developmental Disabilities Prevention Act of 2003.

If you wish further details on the estimate, we will be pleased to provide them. The CBO staff contact is Jeanne De Sa.

Sincerely,

DOUGLAS HOLTZ-EAKIN, *Director.*

Enclosure.

H.R. 398—Birth Defects and Developmental Disabilities Prevention Act of 2003

Summary: H.R. 398 would amend the Public Health Service Act to reauthorize and clarify activities conducted by the National Center on Birth Defects and Developmental Disabilities of the Centers for Disease Control and Prevention (CDC). The bill would authorize the appropriation of such sums as may be necessary for fiscal years 2003 through 2007 for that purpose. (The previous authorization for the National Center on Birth Defects and Developmental Disabilities expired at the end of fiscal year 2002.) Additionally, the bill would change the allotment formula for grants to State Councils on Developmental Disabilities.

Assuming appropriation of the necessary amounts (including annual adjustments for anticipated inflation), CBO estimates that implementing H.R. 398 would cost \$29 million in 2004 and \$350 million over the 2004–2008 period. (Without such inflation adjustments, the change in outlays would total \$340 million over the 2004–2008 period.) Enacting this legislation would not affect direct spending or revenues.

H.R. 398 contains no intergovernmental or private-sector mandates as defined in the Unfunded Mandates Reform Act (UMRA) and would impose no costs on state, local, or tribal governments.

Estimated cost to the Federal Government: The estimated budgetary impact of H.R. 398 is shown in the following table. The costs of this legislation fall within budget function 550 (health).

	By fiscal year, in millions of dollars					
	2003	2004	2005	2006	2007	2008
SPENDING SUBJECT TO APPROPRIATION						
CDC Spending Under Current Law for Birth Defects and Developmental Disabilities						
Estimated Budget Authority ¹	91	0	0	0	0	0
Estimated Outlays	29	40	16	3	2	0
Proposed Changes ²						
Estimated Authorization Level	0	93	95	97	100	0
Estimated Outlays	0	29	71	89	95	66
CDC Spending Under H.R. 398 for Birth Defects and Developmental Disabilities						
Estimated Authorization Level ¹	91	93	95	97	100	0
Estimated Outlays	29	69	87	93	96	66

¹ Since no full-year appropriation has been enacted for 2003, the CDC is operating under a continuing resolution. Therefore, the 2003 level equals the amount appropriated for 2002 under CDC's National Center for Birth Defects and Developmental Disabilities program.

² The amounts shown reflect adjustments for anticipated inflation for those activities for which the bill would authorize such sums as necessary. Without such inflation adjustments, the five-year changes in authorization levels would total \$372 million (instead of \$385 million) and the changes in outlays would total \$340 million (instead of \$350 million).

Basis of estimate: For this estimate, CBO assumes H.R. 398 will be enacted by the end of this fiscal year, and that the necessary amounts will be appropriated for each year.

CDC's National Center on Birth Defects and Developmental Disabilities conducts a range of data collection and research activities related to the prevention of birth defects and developmental disabilities. Those activities include surveillance and monitoring of birth defects and developmental disabilities such as mental retardation, cerebral palsy, and autism, research on the causes of birth defects, and an educational campaign to increase the consumption of folic acid to prevent spina bifida and anencephaly. Other activities focus on surveillance and prevention of Fetal Alcohol Syndrome and identification of ways to address the public health needs of persons with disabilities. In fiscal year 2002, the center's appropriation was \$91 million.

H.R. 398 would reauthorize the center's activities for the 2003–2007 period and would provide such sums as may be necessary for that purpose. Additionally, the bill would clarify that the center's activities should encompass data collection on disabilities and health, research on the prevention of birth defects and disabilities and the prevention of secondary health conditions among people with disabilities, and support for a National Spina Bifida program. According to CDC, the center currently conducts those activities. Therefore, the clarifications in H.R. 398 would not result in a broader set of authorized activities, and this estimate assumes full-

year funding for 2003 at the continuing resolution level of \$91 million.

Based on the amount appropriated for the center in fiscal year 2002 and taking into account anticipated inflation, CBO estimates that the center would require \$385 million for fiscal years 2004 through 2007. Assuming appropriation of the necessary amounts and spending consistent with historical outlay rates, CBO estimates that implementing the bill would cost \$29 million in 2004 and \$350 million over the 2004–2008 period.

H.R. 398 also would make a technical change to the allotment formula for grants to State Councils on Developmental Disabilities, a program in which states use federal grant funds to provide services to individuals with disabilities. CBO estimates this change would have no effect on federal spending.

Intergovernmental and private-sector impact: H.R. 398 contains no intergovernmental or private-sector mandates as defined in UMRA and would impose no costs on state, local, or tribal governments.

Estimate prepared by: Federal Costs: Jeanne De Sa. Impact on State, Local, and Tribal Governments: Leo Lex. Impact on the Private Sector: Samuel Kina.

Estimate approved by: Peter H. Fontaine, Deputy Assistant Director for Budget Analysis.

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

ADVISORY COMMITTEE STATEMENT

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

CONSTITUTIONAL AUTHORITY STATEMENT

Pursuant to clause 3(d)(1) of rule XIII of the Rules of the House of Representatives, the Committee finds that the Constitutional authority for this legislation is provided in Article I, section 8, clause 3, which grants Congress the power to regulate commerce with foreign nations, among the several States, and with the Indian tribes.

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.

SECTION-BY-SECTION ANALYSIS OF THE LEGISLATION

Section 1. Short title

This section provides the short title of the bill, the Birth Defects and Developmental Disabilities Prevention Act of 2003.

Section 2. National Center on Birth Defects and Developmental Disabilities

Section 2 amends section 317C of the Public Health Service Act to authorize the CDC National Center on Birth Defects and Developmental Disabilities (NCBDD) to collect, analyze, and make data available on birth defects, developmental disabilities, and disabilities and health. In addition, NCBDD will conduct research and programs on the prevention of secondary conditions and the promotion of health and wellness in individuals living with disabilities. NCBDD will also support a National Spina Bifida Program to prevent and reduce suffering from the nation's most common permanently disabling birth defect. This section strikes the additional statutory requirement for the NCBDD to collect and analyze data. This section also replaces existing requirements to be included in a biennial report to relevant congressional committees on the activities of the NCBDD with new requirements, including greater information on the incidence and prevalence of birth defects, developmental disabilities, and the health status of individuals with disabilities. Finally, this section formally establishes an Advisory Committee, with members appointed by the Director of the National Center for Environmental Health with expertise in birth defects, developmental disabilities, and disabilities, to advise the NCBDD. Authorization of appropriations for the NCBDD is permitted at a level of such sums as may be necessary for each of fiscal years 2003 through 2007.

Section 3. Technical corrections for State Councils on Developmental Disabilities

This section amends section 122(a) of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 to insert an additional consideration in the allotment for appropriations to States for funding Developmental Disabilities Councils. When appropriating dollars to states, this section states that the allotment may not be less than \$400,000, the amount received by the state for the previous year, or the amount of Federal appropriations received in fiscal year 2000, 2001, or 2002, whichever is greater if the amount appropriated in a fiscal year is less than \$70,000,000. If the amount appropriated in a fiscal year is more than \$70,000,000, then state allotments may not be less than \$450,000, the amount received by the state for the previous year, or the amount of Federal appropriations received in fiscal year 2000, 2001, or 2002, whichever is greater.

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 *italic*, existing law in which no change is proposed is shown in roman):

SECTION 317C OF THE PUBLIC HEALTH SERVICE ACT

NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES

SEC. 317C. (a) IN GENERAL.—

(1) * * *

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

(A) to collect, analyze, and make available data on birth defects **and developmental disabilities**, *developmental disabilities, and disabilities and health* (in a manner that facilitates compliance with **subsection (d)(2)** *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; **and**

(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.

* * * * *

[(b) ADDITIONAL PROVISIONS REGARDING COLLECTION OF DATA.—

[(1) IN GENERAL.—In carrying out subsection (a)(2)(A), the Secretary—

[(A) shall collect and analyze data by gender and by racial and ethnic group, including Hispanics, non-Hispanic whites, Blacks, Native Americans, Asian Americans, and Pacific Islanders;

[(B) shall collect data under subparagraph (A) from birth certificates, death certificates, hospital records, and such other sources as the Secretary determines to be appropriate; and

[(C) shall encourage States to establish or improve programs for the collection and analysis of epidemiological data on birth defects, and to make the data available.

[(2) NATIONAL CLEARINGHOUSE.—In carrying out subsection (a)(1), the Secretary shall establish and maintain a National Information Clearinghouse on Birth Defects to collect and disseminate to health professionals and the general public information on birth defects, including the prevention of such defects.**]**

[(c) (b) GRANTS AND CONTRACTS.—

(1) * * *

* * * * *

[(d) (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—

[(1) contains information regarding the incidence and prevalence of birth defects and the extent to which birth defects have contributed to the incidence and prevalence of infant mortality;]

(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;

* * * * *

(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; [and]

(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

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

[(e)] (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, *including section 444 of the General Education Provisions Act*, shall apply to the data and information that is collected under this section, *except that the Centers for Disease Control and Prevention shall have access to information under section 444(b)(1)(F) of such Act solely for purposes of carrying out subsection (a)(2) of this section and shall otherwise comply with all other requirements of such section 444.*

(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 [\$30,000,000 for fiscal year 1999, \$40,000,000 for fiscal year 2000, and such sums as may be necessary for each of the fiscal years

2001 and 2002.】 *such sums as may be necessary for each of fiscal years 2003 through 2007.*

SECTION 122 OF THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT OF 2000

SEC. 122. STATE ALLOTMENTS.

(a) ALLOTMENTS.—

(1) * * *

* * * * *

(3) MINIMUM ALLOTMENT FOR APPROPRIATIONS LESS THAN OR EQUAL TO \$70,000,000.—

(A) IN GENERAL.—Except as provided in paragraph (4), for any fiscal year the allotment under this section—

(i) * * *

(ii) to any State not described in clause (i) may not be less than \$400,000, *the amount received by the State for the previous year, or the amount of Federal appropriations received in fiscal year 2000, 2001, or 2002, whichever is greater.*

* * * * *

(4) MINIMUM ALLOTMENT FOR APPROPRIATIONS IN EXCESS OF \$70,000,000.—

(A) IN GENERAL.—In any case in which the total amount appropriated under section 129 for a fiscal year is more than \$70,000,000, the allotment under this section for such fiscal year—

(i) * * *

(ii) to any State not described in clause (i) may not be less than \$450,000, *the amount received by the State for the previous year, or the amount of Federal appropriations received in fiscal year 2000, 2001, or 2002, whichever is greater.*

* * * * *