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BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES PREVENTION ACT OF 2003

NOVEMBER 6, 2003.—Ordered to be printed

Mr. GREGG, from the Committee on Health, Education, Labor, and Pensions, submitted the following

R E P O R T

[To accompany S. 286]

The Committee on Health, Education, Labor, and Pensions, to which was referred the bill (S. 286) to revise and extend the Birth Defects Prevention Act of 1998, having considered the same, reports favorably thereon with an amendment in the nature of a substitute and recommends that the bill (as amended) do pass.

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I. PURPOSE AND NEED FOR LEGISLATION

There is still much work to be done to improve the health of all Americans by preventing birth defects and developmental disabilities in children. Of the four million babies born each year in the United States, approximately 150,000 are born with one or more serious birth defects. Birth defects are the leading cause of infant mortality and responsible for about 30 percent of all pediatric hospital admissions. The lifetime economic costs of caring for infants born in a single year with a serious birth defect have been esti-

mated at $8 billion. The causes of about 70 percent of birth defects are still unknown.

About 17 percent of U.S. children under 18 years of age have a developmental disability. 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. In most instances, the cause of the disability is not known. State and Federal education departments spend about $36 billion each year on special education programs for individuals with developmental disabilities who are 3–21 years old.

In 1998, Congress passed the Birth Defects Prevention Act (P.L. 105–168), which authorized CDC to provide surveillance, research, and services aimed at the prevention of birth defects. Then Congress passed the Children's Health Act of 2000 (P.L. 106–310), which established the National Center on Birth Defects and Developmental Disabilities at CDC to focus on improving the health of children by preventing birth defects and developmental disabilities. Authorization of appropriations for the National Center on Birth Defects and Developmental Disabilities expired in fiscal year 2002.

II. SUMMARY

S. 286, the Birth Defects and Developmental Disabilities Prevention Act, reauthorizes the activities of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC). The legislation authorizes the full scope of activities being conducted by NCBDDD.

In addition, the Birth Defects and Developmental Disabilities Prevention Act amends the Family Educational Rights and Privacy Act to authorize the CDC to collect data from educational records necessary for data collection on developmental disabilities (such as autism and fetal alcohol syndrome).

III. HISTORY OF LEGISLATION AND VOTES IN COMMITTEE

On February 4, 2003, Senator Bond, for himself and Senators Dodd, Frist and Kennedy, introduced S. 286, to revise and extend the Birth Defects Prevention Act of 1998.

On February 12, 2003, the committee held an executive session to consider S. 286. The committee approved S. 286 by unanimous voice vote.

IV. EXPLANATION OF BILL AND COMMITTEE VIEWS

The Committee sought to authorize the full scope of activities for the National Center on Birth Defects and Developmental Disabilities, including data collection and analysis on not only birth defects, but also developmental disabilities.

In addition, the committee establishes a new national program on Spina Bifida at the CDC, recognizing the importance of addressing this condition. Spina Bifida is the most common, permanently disabling birth defect consistent with life and it is largely preventable. To date, very few Federal efforts have been directed toward surveillance, prevention, basic research and quality of life interventions for Spina Bifida. The committee recognizes critical advances in the practice of medicine and public health interventions that

could prevent this tragic disease or intervene early enough during pregnancy to mitigate its effects.

The committee recognizes the importance of allowing the CDC to access educational records as part of its research on developmental disabilities. The bill amends the Family Educational Rights and Privacy Act to allow the CDC to access educational records for public health research related to developmental disabilities such as autism.

The committee is pleased that the congressionally mandated Spina Bifida Research Conference, sponsored by the CDC, occurred in May this year and the bill provides that recommendations arising from this conference be included in the Secretary's report on the activities of the NCBDDD.

The bill improves the ability of the NCBDDD to obtain technical, scientific and stakeholder input by shifting the birth defects expertise from the Advisory Committee at the National Center for Environmental Health to an Advisory Committee for the NCBDDD.

The bill corrects a formula error affecting State Developmental Disabilities Councils.

V. COST ESTIMATE

U.S. CONGRESS,
CONGRESSIONAL BUDGET OFFICE,
Washington, DC, March 5, 2003.

Hon. JUDD GREGG,
Chairman, Committee on Health, Education, Labor, and Pensions, U.S. Senate, Washington, DC.

DEAR MR. CHAIRMAN: The Congressional Budget Office has prepared the enclosed cost estimate for S. 286, the Birth Defects and Developmental Disabilities Prevention Act of 2003.

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

Sincerely,

DOUGLAS HOLTZ-EAKIN,
Director.

Enclosure.

S. 286—Birth Defects and Developmental Disabilities Prevention Act of 2003

Summary: S. 286 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 S. 286 would cost $32 million in 2004 and $381 million over the 2004–2008 period. (Without such inflation adjustments, the change in outlays would total $369 million over the 2004–2008

period.) Enacting this legislation would not affect direct spending or revenues.

S. 286 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 S. 286 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:						
Budget Authority [1]	99	0	0	0	0	0
Estimated Outlays	31	44	18	4	2	0
Proposed Changes [2]:						
Estimated Authorization Level	0	101	103	106	108	0
Estimated Outlays	0	32	77	97	103	72
CDC Spending Under S. 286 for Birth Defects and Developmental Disabilities:						
Estimated Authorization Level [1]	99	101	103	106	108	0
Estimated Outlays	31	76	95	101	105	72

[1] The 2003 figure is the amount appropriated for that year for activities 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 $404 million (instead of $418 million) and the changes in outlays would total $369 million (instead of $381 million).

Basis of estimate: For this estimate, CBO assumes S. 286 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. The center's appropriation for fiscal year 2003 is $99 million.

S. 286 would reauthorize the center's activities for the 2003–2007 period and would authorize appropriations of 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 such activities. Therefore, the clarifications in S. 286 would not result in a broader set of authorized activities.

Based on the amount appropriated for the center in fiscal year 2003 and taking into account anticipated inflation, CBO estimates that the center would require appropriations of $418 million for fiscal years 2004 and 2007. Assuming appropriation of such amounts and spending consistent with historical outlay rates, CBO esti-

mates that implementing the bill would result in outlays of $32 million in 2004 and $381 million over the 2004–2008 period.

S. 286 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: S. 286 contains no intergovernmental or private-sector mandates as defined in UMRA and would impose no costs on state, local, or tribal governments.

Previous CBO estimate: On February 11, 2003, CBO transmitted a cost estimate for H.R. 398, the Birth Defects and Developmental Disabilities Act of 2003, as ordered reported by the House Committee on Energy and Commerce on January 28, 2003. The bills are identical. CBO estimated that H.R. 398 would increase by $29 million in 2004 and $350 million over the 2004–2008 period—$3 million and $31 million lower, respectively, than the current estimate. The difference is due entirely to higher projections of spending under current law as a result of enactment of the omnibus appropriations act (P.L. 108–7).

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

Estimate approved by: Robert A. Sunshine, Assistant Director for Budget Analysis.

VI. Regulatory Impact Statement

The committee has determined that there will be minimal increases in the regulatory burden imposed by this bill.

VII. Application of Law to the Legislative Branch

The Committee has determined that there is no legislative impact.

VIII. Section-by-Section Analysis

Section 1. Short title

Section 1 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 National Center on Birth Defects and Developmental Disabilities to collect, analyze, and make available data on disabilities and health in addition to birth defects and developmental disabilities. In addition, NCBDDD has authority to support a National Spina Bifida Program to promote prevention and enhance the quality of life for those living with Spina Bifida. This section gives NCBDDD authority to conduct research and programs on the prevention of secondary conditions and the promotion of health and wellness in individuals living with disabilities. It amends the Family Educational Rights and Privacy Act to authorize NCBDDD to collect data from educational records that are necessary to con-

duct surveillance research on developmental disabilities while protecting the privacy of individuals and their families. This section also requires a biennial report to relevant congressional committees on the activities of the Center on Birth Defects and Developmental Disabilities including birth defects, developmental disabilities and disabilities and health. This report must include a summary of the recommendations from the 2003 Research Conference on Spina Bifida sponsored by the CDC, in collaboration with the Agency for Healthcare Research and Quality and individual institutes at the National Institutes of Health. Finally, this section transfers members of the Advisory Committee to the Director of the National Center for Environmental Health that have expertise in birth defects, developmental disabilities and disabilities and health to the Center on Birth Defects and Developmental Disabilities. The membership includes scientific experts, state health department representatives and parents of a child with a birth defect or groups concerned with birth defects, developmental disabilities and individuals living with a disability. Authorization of appropriations for the NCBDDD 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

Section 3 amends section 122(a) of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 to insert 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 fiscal years, or the amount of Federal appropriations received in fiscal year 2000, 2001, or 2002, whichever is greater.

IX. Changes in Existing Law

In compliance with rule XXVI paragraph 12 of the Standing Rules of the Senate, the following provides a print of the statute or the part or section thereof to be amended or replaced (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):

PUBLIC HEALTH SERVICE ACT

* * * * * * *

Birth Defects and Developmental Disabilities Prevention Act of 2003

* * * * * * *

TITLE III—GENERAL POWERS AND DUTIES OF PUBLIC HEALTH SERVICE

PART A—RESEARCH AND INVESTIGATION

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PART B—FEDERAL-STATE COOPERATION

* * * * * * *

NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES

SEC. 371C. (a) IN GENERAL.—

(1) NATIONAL CENTER.—* * *

(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 dis-

seminate to health professionals and the general public information on birth defects, including the prevention of such defects.]

[(c)] *(b)* GRANTS AND CONTRACTS.—

* * * * * * *

[(d) *(c)*] BIENNIAL REPORT.—* * *

[(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 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 [$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.*

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DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT OF 2000

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Subtitle B—Federal Assistance to State Councils on Developmental Disabilities

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SEC. 122. STATE ALLOTMENTS.

(a) ALLOTMENTS.—

(1) IN GENERAL.—

* * * * * * *

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

(A) IN GENERAL.—* * *

(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.— * * *

(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*.

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