

108TH CONGRESS  
1ST SESSION

# S. 286

---

## AN ACT

To revise and extend the Birth Defects Prevention Act of  
1998.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Birth Defects and De-  
5 velopmental Disabilities Prevention Act of 2003”.

1 **SEC. 2. NATIONAL CENTER ON BIRTH DEFECTS AND DE-**  
2 **VELOPMENTAL DISABILITIES.**

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

5 (1) in subsection (a)(2)—

6 (A) in subparagraph (A)—

7 (i) by striking “and developmental  
8 disabilities” and inserting “, developmental  
9 disabilities, and disabilities and health”;  
10 and

11 (ii) by striking “subsection (d)(2)”  
12 and inserting “subsection (c)(2)”;

13 (B) in subparagraph (B), by striking  
14 “and” at the end;

15 (C) in subparagraph (C), by striking the  
16 period and inserting a semicolon; and

17 (D) by adding at the end the following:

18 “(D) to conduct research on and to pro-  
19 mote the prevention of such defects and disabil-  
20 ities, and secondary health conditions among in-  
21 dividuals with disabilities; and

22 “(E) to support a National Spina Bifida  
23 Program to prevent and reduce suffering from  
24 the Nation’s most common permanently dis-  
25 abling birth defect.”;

26 (2) by striking subsection (b);

1 (3) in subsection (d)—

2 (A) by striking paragraph (1) and insert-  
3 ing the following:

4 “(1) contains information regarding the inci-  
5 dence and prevalence of birth defects, developmental  
6 disabilities, and the health status of individuals with  
7 disabilities and the extent to which these conditions  
8 have contributed to the incidence and prevalence of  
9 infant mortality and affected quality of life;”;

10 (B) in paragraph (3), by inserting “, devel-  
11 opmental disabilities, and secondary health con-  
12 ditions among individuals with disabilities”  
13 after “defects”;

14 (C) in paragraph (4), by striking “and” at  
15 the end;

16 (D) by redesignating paragraph (5) as  
17 paragraph (7); and

18 (E) by inserting after paragraph (4) the  
19 following:

20 “(5) contains information on the incidence and  
21 prevalence of individuals living with birth defects  
22 and disabilities or developmental disabilities, infor-  
23 mation on the health status of individuals with dis-  
24 abilities, information on any health disparities expe-  
25 rienced by such individuals, and recommendations

1 for improving the health and wellness and quality of  
2 life of such individuals;

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

7 (4) by redesignating subsections (c), (d), and  
8 (e) as subsections (b), (c), and (d), respectively;

9 (5) by inserting after subsection (d) (as so re-  
10 designated), the following:

11 “(e) ADVISORY COMMITTEE.—Notwithstanding any  
12 other provision of law, the members of the advisory com-  
13 mittee appointed by the Director of the National Center  
14 for Environmental Health that have expertise in birth de-  
15 fects, developmental disabilities, and disabilities and  
16 health shall be transferred to and shall advise the National  
17 Center on Birth Defects and Developmental Disabilities  
18 effective on the date of enactment of the Birth Defects  
19 and Developmental Disabilities Prevention Act of 2003.”;  
20 and

21 (6) in subsection (f), by striking “\$30,000,000”  
22 and all that follows and inserting “such sums as  
23 may be necessary for each of fiscal years 2003  
24 through 2007.”.

1 **SEC. 3. TECHNICAL CORRECTIONS FOR STATE COUNCILS**  
2 **ON DEVELOPMENTAL DISABILITIES.**

3 (a) **IN GENERAL.**—Section 122(a) of the Develop-  
4 mental Disabilities Assistance and Bill of Rights Act of  
5 2000 (42 U.S.C. 15022(a)) is amended—

6 (1) in paragraph (3)(A)(ii), by inserting before  
7 the period the following: “, the amount received by  
8 the State for the previous year, or the amount of  
9 Federal appropriations received in fiscal year 2000,  
10 2001, or 2002, whichever is greater”; and

11 (2) in paragraph (4)(A)(ii), by inserting before  
12 the period the following: “, the amount received by  
13 the State for the previous year, or the amount of  
14 Federal appropriations received in fiscal year 2000,  
15 2001, or 2002, whichever is greater”.

16 (b) **EFFECTIVE DATE.**—The amendments made by  
17 subsection (a) shall take effect on October 1, 2003 and  
18 apply to allotments beginning in fiscal year 2004.

19 **SEC. 4. REPORT ON SURVEILLANCE ACTIVITIES.**

20 Not later than 18 months after the date of enactment  
21 of this Act, the Secretary of Health and Human Services  
22 jointly with the Secretary of Education shall submit to the  
23 Committee on Health, Education, Labor, and Pensions of  
24 the Senate and the Committee on Energy and Commerce  
25 and Committee on Education and the Workforce of the  
26 House of Representatives a report concerning surveillance

1 activities under section 102 of the Children’s Health Act  
2 of 2000 (Public Law 106-310), specifically including—

3           (1) a description of the current grantees under  
4 the National Autism and Pervasive Developmental  
5 Disabilities Surveillance Program and the Centers of  
6 Excellence in Autism and Pervasive Developmental  
7 Disabilities the data collected, analyzed, and re-  
8 ported under such grants, the sources of such data,  
9 and whether such data was obtained with parental  
10 consent as required under the Family Educational  
11 Rights and Privacy Act of 1974 (20 U.S.C. 1232g);

12           (2) a description of current sources of data for  
13 the surveillance of autism and developmental disabil-  
14 ities and the methods for obtaining such data, in-  
15 cluding whether such data was obtained with paren-  
16 tal or patient consent for disclosure;

17           (3) an analysis of research on autism and devel-  
18 opmental disabilities with respect to the methods of  
19 collection and reporting, including whether such re-  
20 search was obtained with parental or patient consent  
21 for disclosure;

22           (4) an analysis of the need to add education  
23 records in the surveillance of autism and other devel-  
24 opmental disabilities, including the methodological  
25 and medical necessity for such records and the

1 rights of parents and patients in the use of edu-  
2 cation records (in accordance with the Family Edu-  
3 cational Rights and Privacy Act of 1974);

4 (5) a description of the efforts taken by the  
5 Centers for Disease Control and Prevention to uti-  
6 lize education records in conducting the surveillance  
7 program while obtaining parental or patient consent  
8 for such education records, including the outcomes  
9 of such efforts;

10 (6) a description of the challenges provided to  
11 obtaining education records (in the absence of pa-  
12 rental or patient consent) for the purpose of obtain-  
13 ing additional surveillance data for autism and other  
14 developmental disabilities; and

15 (7) a description of the manner in which such  
16 challenges can be overcome, including efforts to edu-  
17 cate parents, increase confidence in the privacy of  
18 the surveillance program, and increase the rate of  
19 parental or patient consent, and including specific  
20 quantitative and qualitative justifications for any  
21 recommendations for changes to existing statutory

1 authority, including the Family Educational Rights  
2 and Privacy Act of 1974.

Passed the Senate November 11, 2003.

Attest:

*Secretary.*

108TH CONGRESS  
1ST SESSION

**S. 286**

---

---

**AN ACT**

To revise and extend the Birth Defects Prevention  
Act of 1998.