

108TH CONGRESS  
1ST SESSION

# S. 1226

To coordinate efforts in collecting and analyzing data on the incidence and prevalence of developmental disabilities, and for other purposes.

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IN THE SENATE OF THE UNITED STATES

JUNE 10, 2003

Mrs. CLINTON (for herself, Ms. COLLINS, Mrs. MURRAY, and Mr. BINGAMAN)  
introduced the following bill; which was read twice and referred to the  
Committee on Health, Education, Labor, and Pensions

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## A BILL

To coordinate efforts in collecting and analyzing data on  
the incidence and prevalence of developmental disabilities,  
and for other purposes.

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 “2003 Act to Prevent  
5       Developmental Disabilities in Education”.

6       **SEC. 2. FINDINGS AND PURPOSES.**

7       (a) FINDINGS.—Congress makes the following find-  
8       ings:

1           (1) Seventeen percent of children in the United  
2 States under 18 years of age have a developmental  
3 disability.

4           (2) Since 1977, enrollment in special education  
5 programs for children with learning disabilities has  
6 doubled.

7           (3) Federal and State education departments  
8 spend about \$43,000,000,000 each year on special  
9 education programs for individuals with develop-  
10 mental disabilities who are between 3 and 21 years  
11 of age.

12           (4) Research suggests that genetic factors ex-  
13 plain only 10 to 20 percent of developmental dis-  
14 eases, and a National Academy of Sciences study  
15 suggests that at least 28 percent of developmental  
16 disabilities are due to environmental causes.

17           (b) PURPOSE.—It is the purpose of this Act to ensure  
18 a collaborative tracking effort between the Department of  
19 Education and the Centers for Disease Control and Pre-  
20 vention for developmental disabilities and potential envi-  
21 ronmental links.

22 **SEC. 3. DEPARTMENT OF EDUCATION TRACKING ACTIVI-**  
23 **TIES.**

24           (a) IN GENERAL.—The Secretary of Education (in  
25 this section referred to as the “Secretary”) shall coordi-

1 nate efforts with the Director of the National Center for  
2 Birth Defects and Developmental Disabilities of the Cen-  
3 ters for Disease Control and Prevention (in this section  
4 referred to as the “Director”) in collecting and analyzing  
5 data on the incidence and prevalence of developmental dis-  
6 abilities to determine localities with a high incidence of  
7 developmental disabilities and study possible causes of the  
8 increased incidence of these diseases, disorders, and condi-  
9 tions.

10 (b) EXISTING SURVEILLANCE SYSTEMS, REGISTRIES,  
11 AND SURVEYS.—To the maximum extent practicable in  
12 implementing the activities under this section, the Sec-  
13 retary and the Director shall develop methods for recon-  
14 ciling data collected in accordance with the Individuals  
15 with Disabilities Education Act (20 U.S.C. 1400 et seq.)  
16 on the prevalence of developmental disabilities with exist-  
17 ing surveillance and data collection systems, registries,  
18 and surveys that are administered by the Centers for Dis-  
19 ease Control and Prevention, including—

- 20 (1) State birth defects surveillance systems as  
21 supported under section 317C of the Public Health  
22 Service Act (42 U.S.C. 247b–4); and  
23 (2) environmental public health tracking pro-  
24 gram grants authorized under section 301 of the  
25 Public Health Service Act (42 U.S.C. 241).

1       (c) PRIVACY.—In pursuing activities under this sec-  
2 tion, the Secretary and the Director shall ensure the pro-  
3 tection of individual health privacy consistent with regula-  
4 tions promulgated in accordance with section 264(c) of the  
5 Health Insurance Portability and Accountability Act of  
6 1996 (42 U.S.C. 1320d–2 note), the Family Educational  
7 Right to Privacy Act (20 U.S.C. 1232g), and State and  
8 local privacy regulations, as applicable.

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