

110TH CONGRESS
2D SESSION

S. 1810

IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 24, 2008

Referred to the Committee on Energy and Commerce

AN ACT

To amend the Public Health Service Act to increase the provision of scientifically sound information and support services to patients receiving a positive test diagnosis for Down syndrome or other prenatally and postnatally diagnosed conditions.

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

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Prenatally and
3 Postnatally Diagnosed Conditions Awareness Act”.

4 **SEC. 2. PURPOSES.**

5 It is the purpose of this Act to—

6 (1) increase patient referrals to providers of key
7 support services for women who have received a
8 positive diagnosis for Down syndrome, or other pre-
9 natally or postnatally diagnosed conditions, as well
10 as to provide up-to-date information on the range of
11 outcomes for individuals living with the diagnosed
12 condition, including physical, developmental, edu-
13 cational, and psychosocial outcomes;

14 (2) strengthen existing networks of support
15 through the Centers for Disease Control and Preven-
16 tion, the Health Resources and Services Administra-
17 tion, and other patient and provider outreach pro-
18 grams; and

19 (3) ensure that patients receive up-to-date, evi-
20 dence-based information about the accuracy of the
21 test.

22 **SEC. 3. AMENDMENT TO THE PUBLIC HEALTH SERVICE**
23 **ACT.**

24 Part P of title III of the Public Health Service Act
25 (42 U.S.C. 280g et seq.) is amended by adding at the end
26 the following:

1 **“SEC. 399R. SUPPORT FOR PATIENTS RECEIVING A POSI-**
 2 **TIVE DIAGNOSIS OF DOWN SYNDROME OR**
 3 **OTHER PRENATALLY OR POSTNATALLY DIAG-**
 4 **NOSED CONDITIONS.**

5 “(a) DEFINITIONS.—In this section:

6 “(1) DOWN SYNDROME.—The term ‘Down syn-
 7 drome’ refers to a chromosomal disorder caused by
 8 an error in cell division that results in the presence
 9 of an extra whole or partial copy of chromosome 21.

10 “(2) HEALTH CARE PROVIDER.—The term
 11 ‘health care provider’ means any person or entity re-
 12 quired by State or Federal law or regulation to be
 13 licensed, registered, or certified to provide health
 14 care services, and who is so licensed, registered, or
 15 certified.

16 “(3) POSTNATALLY DIAGNOSED CONDITION.—
 17 The term ‘postnatally diagnosed condition’ means
 18 any health condition identified during the 12-month
 19 period beginning at birth.

20 “(4) PRENATALLY DIAGNOSED CONDITION.—
 21 The term ‘prenatally diagnosed condition’ means any
 22 fetal health condition identified by prenatal genetic
 23 testing or prenatal screening procedures.

24 “(5) PRENATAL TEST.—The term ‘prenatal
 25 test’ means diagnostic or screening tests offered to
 26 pregnant women seeking routine prenatal care that

1 are administered on a required or recommended
2 basis by a health care provider based on medical his-
3 tory, family background, ethnic background, pre-
4 vious test results, or other risk factors.

5 “(b) INFORMATION AND SUPPORT SERVICES.—

6 “(1) IN GENERAL.—The Secretary, acting
7 through the Director of the National Institutes of
8 Health, the Director of the Centers for Disease Con-
9 trol and Prevention, or the Administrator of the
10 Health Resources and Services Administration, may
11 authorize and oversee certain activities, including the
12 awarding of grants, contracts or cooperative agree-
13 ments to eligible entities, to—

14 “(A) collect, synthesize, and disseminate
15 current evidence-based information relating to
16 Down syndrome or other prenatally or
17 postnatally diagnosed conditions; and

18 “(B) coordinate the provision of, and ac-
19 cess to, new or existing supportive services for
20 patients receiving a positive diagnosis for Down
21 syndrome or other prenatally or postnatally di-
22 agnosed conditions, including—

23 “(i) the establishment of a resource
24 telephone hotline accessible to patients re-
25 ceiving a positive test result or to the par-

1 ents of newly diagnosed infants with Down
2 syndrome and other diagnosed conditions;

3 “(ii) the expansion and further devel-
4 opment of the National Dissemination
5 Center for Children with Disabilities, so
6 that such Center can more effectively con-
7 duct outreach to new and expecting par-
8 ents and provide them with up-to-date in-
9 formation on the range of outcomes for in-
10 dividuals living with the diagnosed condi-
11 tion, including physical, developmental,
12 educational, and psychosocial outcomes;

13 “(iii) the expansion and further devel-
14 opment of national and local peer-support
15 programs, so that such programs can more
16 effectively serve women who receive a posi-
17 tive diagnosis for Down syndrome or other
18 prenatal conditions or parents of infants
19 with a postnatally diagnosed condition;

20 “(iv) the establishment of a national
21 registry, or network of local registries, of
22 families willing to adopt newborns with
23 Down syndrome or other prenatally or
24 postnatally diagnosed conditions, and links
25 to adoption agencies willing to place babies

1 with Down syndrome or other prenatally or
 2 postnatally diagnosed conditions, with fam-
 3 ilies willing to adopt; and

4 “(v) the establishment of awareness
 5 and education programs for health care
 6 providers who provide, interpret, or inform
 7 parents of the results of prenatal tests for
 8 Down syndrome or other prenatally or
 9 postnatally diagnosed conditions, to pa-
 10 tients, consistent with the purpose de-
 11 scribed in section 2(b)(1) of the Prenatally
 12 and Postnatally Diagnosed Conditions
 13 Awareness Act.

14 “(2) ELIGIBLE ENTITY.—In this subsection, the
 15 term ‘eligible entity’ means—

16 “(A) a State or a political subdivision of a
 17 State;

18 “(B) a consortium of 2 or more States or
 19 political subdivisions of States;

20 “(C) a territory;

21 “(D) a health facility or program operated
 22 by or pursuant to a contract with or grant from
 23 the Indian Health Service; or

24 “(E) any other entity with appropriate ex-
 25 pertise in prenatally and postnatally diagnosed

1 conditions (including nationally recognized dis-
2 ability groups), as determined by the Secretary.

3 “(3) DISTRIBUTION.—In distributing funds
4 under this subsection, the Secretary shall place an
5 emphasis on funding partnerships between health
6 care professional groups and disability advocacy or-
7 ganizations.

8 “(c) PROVISION OF INFORMATION TO PROVIDERS.—

9 “(1) IN GENERAL.—A grantee under this sec-
10 tion shall make available to health care providers of
11 parents who receive a prenatal or postnatal diag-
12 nosis the following:

13 “(A) Up-to-date, evidence-based, written
14 information concerning the range of outcomes
15 for individuals living with the diagnosed condi-
16 tion, including physical, developmental, edu-
17 cational, and psychosocial outcomes.

18 “(B) Contact information regarding sup-
19 port services, including information hotlines
20 specific to Down syndrome or other prenatally
21 or postnatally diagnosed conditions, resource
22 centers or clearinghouses, national and local
23 peer support groups, and other education and
24 support programs as described in subsection
25 (b)(2).

1 “(2) INFORMATIONAL REQUIREMENTS.—Infor-
2 mation provided under this subsection shall be—

3 “(A) culturally and linguistically appro-
4 priate as needed by women receiving a positive
5 prenatal diagnosis or the family of infants re-
6 ceiving a postnatal diagnosis; and

7 “(B) approved by the Secretary.

8 “(d) REPORT.—Not later than 2 years after the date
9 of enactment of this section, the Government Account-
10 ability Office shall submit a report to Congress concerning
11 the effectiveness of current healthcare and family support
12 programs serving as resources for the families of children
13 with disabilities.”.

 Passed the Senate September 23 (legislative day,
September 17), 2008.

Attest:

NANCY ERICKSON,
Secretary.