

One Hundred Tenth Congress
of the
United States of America

AT THE SECOND SESSION

*Begun and held at the City of Washington on Thursday,
the third day of January, two thousand and eight*

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.

*Be it enacted by the Senate and House of Representatives of
the United States of America in Congress assembled,*

SECTION 1. SHORT TITLE.

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

SEC. 2. PURPOSES.

It is the purpose of this Act to—

(1) increase patient referrals to providers of key support services for women who have received a positive diagnosis for Down syndrome, or other prenatally or postnatally diagnosed conditions, as well as to provide up-to-date information on the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes;

(2) strengthen existing networks of support through the Centers for Disease Control and Prevention, the Health Resources and Services Administration, and other patient and provider outreach programs; and

(3) ensure that patients receive up-to-date, evidence-based information about the accuracy of the test.

SEC. 3. AMENDMENT TO THE PUBLIC HEALTH SERVICE ACT.

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

“SEC. 399R. SUPPORT FOR PATIENTS RECEIVING A POSITIVE DIAGNOSIS OF DOWN SYNDROME OR OTHER PRENATALLY OR POSTNATALLY DIAGNOSED CONDITIONS.

“(a) DEFINITIONS.—In this section:

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

“(2) HEALTH CARE PROVIDER.—The term ‘health care provider’ means any person or entity required by State or Federal law or regulation to be licensed, registered, or certified to provide health care services, and who is so licensed, registered, or certified.

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

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

“(5) PRENATAL TEST.—The term ‘prenatal test’ means diagnostic or screening tests offered to pregnant women seeking routine prenatal care that are administered on a required or recommended basis by a health care provider based on medical history, family background, ethnic background, previous test results, or other risk factors.

“(b) INFORMATION AND SUPPORT SERVICES.—

“(1) IN GENERAL.—The Secretary, acting through the Director of the National Institutes of Health, the Director of the Centers for Disease Control and Prevention, or the Administrator of the Health Resources and Services Administration, may authorize and oversee certain activities, including the awarding of grants, contracts or cooperative agreements to eligible entities, to—

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

“(B) coordinate the provision of, and access to, new or existing supportive services for patients receiving a positive diagnosis for Down syndrome or other prenatally or postnatally diagnosed conditions, including—

“(i) the establishment of a resource telephone hotline accessible to patients receiving a positive test result or to the parents of newly diagnosed infants with Down syndrome and other diagnosed conditions;

“(ii) the expansion and further development of the National Dissemination Center for Children with Disabilities, so that such Center can more effectively conduct outreach to new and expecting parents and provide them with up-to-date information on the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes;

“(iii) the expansion and further development of national and local peer-support programs, so that such programs can more effectively serve women who receive a positive diagnosis for Down syndrome or other prenatal conditions or parents of infants with a postnatally diagnosed condition;

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

“(v) the establishment of awareness and education programs for health care providers who provide, interpret, or inform parents of the results of prenatal tests for Down syndrome or other prenatally or postnatally

diagnosed conditions, to patients, consistent with the purpose described in section 2(b)(1) of the Prenatally and Postnatally Diagnosed Conditions Awareness Act.

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

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

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

“(C) a territory;

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

“(E) any other entity with appropriate expertise in prenatally and postnatally diagnosed conditions (including nationally recognized disability groups), as determined by the Secretary.

“(3) DISTRIBUTION.—In distributing funds under this subsection, the Secretary shall place an emphasis on funding partnerships between health care professional groups and disability advocacy organizations.

“(c) PROVISION OF INFORMATION TO PROVIDERS.—

“(1) IN GENERAL.—A grantee under this section shall make available to health care providers of parents who receive a prenatal or postnatal diagnosis the following:

“(A) Up-to-date, evidence-based, written information concerning the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes.

“(B) Contact information regarding support services, including information hotlines specific to Down syndrome or other prenatally or postnatally diagnosed conditions, resource centers or clearinghouses, national and local peer support groups, and other education and support programs as described in subsection (b)(2).

“(2) INFORMATIONAL REQUIREMENTS.—Information provided under this subsection shall be—

“(A) culturally and linguistically appropriate as needed by women receiving a positive prenatal diagnosis or the family of infants receiving a postnatal diagnosis; and

“(B) approved by the Secretary.

“(d) REPORT.—Not later than 2 years after the date of enactment of this section, the Government Accountability Office shall submit a report to Congress concerning the effectiveness of current

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healthcare and family support programs serving as resources for the families of children with disabilities.”.

Speaker of the House of Representatives.

*Vice President of the United States and
President of the Senate.*