ASSEMBLY, No. 286

STATE OF NEW JERSEY
218th LEGISLATURE

PRE-FILED FOR INTRODUCTION IN THE 2018 SESSION

Sponsored by:
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SYNOPSIS
"Prenatally and Postnatally Diagnosed Conditions Awareness Act in New Jersey."

CURRENT VERSION OF TEXT
Introduced Pending Technical Review by Legislative Counsel.

(Sponsorship Updated As Of: 3/6/2018)
AN ACT concerning prenatally and postnatally diagnosed conditions
and supplementing Title 26 of the Revised Statutes.

BE IT ENACTED by the Senate and General Assembly of the State
of New Jersey:

1. This act shall be known and may be cited as the "Prenatally
and Postnatally Diagnosed Conditions Awareness Act in New
Jersey."

2. The Legislature finds and declares that it is in the public
interest to increase patient referrals to providers of supportive
services to new or expecting parents who receive positive test
results of a test for Down syndrome and other prenatally or
postnatally diagnosed conditions, to provide these parents with up-
to-date information on the range of outcomes for persons living
with the diagnosed condition, to strengthen support services, and to
provide these parents with information about the accuracy of the
testing for these conditions.

3. As used in this act:
   "Commissioner" means the Commissioner of Health and Senior
   Services;
   "Department" means the Department of Health and Senior
   Services;
   "Down syndrome" means 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;
   "Health care professional" means an individual who, acting
   within the scope of his State licensure or certification, provides
   health care services;
   "Postnatally diagnosed condition" means a health condition
   identified by postnatal genetic testing or postnatal screening
   procedures during the 12-month period beginning at birth;
   "Postnatal test" means a diagnostic or screening test that is
   offered to an individual from birth to one year of age and is
   administered by a health care professional, based on medical
   history, family or ethnic background, previous test results,
symptoms presented by a child, or other risk factors;
   "Prenatally diagnosed condition" means a fetal health condition
   identified by prenatal genetic testing or prenatal screening
   procedures; and
   "Prenatal test" means a diagnostic or screening test that is
   offered to a pregnant woman seeking routine prenatal care and is
   administered by a health care professional, based on medical
   history, family or ethnic background, previous test results, or other
   risk factors.
4. a. The commissioner shall authorize and oversee activities including, but not limited to:

(1) the awarding of grants, contracts, or cooperative agreements to collect and synthesize current evidence-based information relating to Down syndrome and other prenatally or postnatally diagnosed conditions and the testing for these conditions, and to disseminate such information to providers of supportive services as specified in subsection b. of this section and health care professionals treating a new or expecting parent receiving a positive result of a test for Down syndrome or other prenatally or postnatally diagnosed conditions; and

(2) coordinating the provision of and access to supportive services to a new or expecting parent receiving a positive result of a test for Down syndrome or other prenatally or postnatally diagnosed conditions.

In awarding any grants or contracts or entering into any agreements, the commissioner shall give priority to partnerships between health care groups and organizations that advocate for persons with a disability.

b. The supportive services specified in subsection a. of this section shall include, but not be limited to:

(1) the establishment of a telephone hotline to provide information about available resources and services to a new or expecting parent receiving a positive result of a test for Down syndrome or other prenatally or postnatally diagnosed conditions;

(2) current information, posted on the official department website, about available resources and services to a new or expecting parent receiving positive results of a test for Down syndrome or other prenatally or postnatally diagnosed conditions;

(3) the expansion and development, as appropriate, of local peer support programs that effectively serve a woman who receives a prenatal, positive diagnosis for Down syndrome or other prenatal conditions, or a parent of an infant with a postnatally diagnosed condition;

(4) the expansion and development, as appropriate, of networks of providers who provide a new or expecting parent with up-to-date information on the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes; and

(5) the establishment of an awareness and education program, which includes current evidence-based information relating to Down syndrome and other prenatally and postnatally diagnosed conditions, for health care professionals or their designees who provide the results of prenatal or postnatal testing for Down syndrome and other prenatally and postnatally diagnosed conditions to a new or expecting parent.
5. Upon receipt of a positive result of a test for Down syndrome or other prenatally or postnataally diagnosed conditions, the health care professional, or his designee, shall provide a new or expecting parent with:
   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. a referral to a provider of supportive services as described in paragraph (4) of subsection b. of section 4 of this act;
   c. contact information about peer support programs as described in paragraph (3) of subsection b. of section 4 of this act;
   d. information about registries of families willing to adopt newborns with Down syndrome or other prenatally or postnataally diagnosed conditions, and about links to adoption agencies willing to place babies with Down syndrome or other prenatally or postnataally diagnosed conditions with families willing to adopt, established pursuant to the federal "Prenatally and Postnatally Diagnosed Conditions Awareness Act," Pub.L.110-374; and
   e. information about the establishment of a telephone hotline and website, as described in paragraphs (1) and (2) of subsection b. of section 4 of this act.

6. The commissioner shall coordinate the implementation of this act with the federal "Prenatally and Postnatally Diagnosed Conditions Awareness Act," Pub.L.110-374. The commissioner shall seek federal funds for the purposes of this act, but there shall be no State funds appropriated to the department in Fiscal Year 2009 for the purposes of this act.

7. Pursuant to the "Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et seq.), the commissioner shall adopt rules and regulations necessary to effectuate the purposes of this act.

8. This act shall take effect 180 days following the date of enactment.

STATEMENT

This bill, which is designated the "Prenatally and Postnatally Diagnosed Conditions Awareness Act in New Jersey," concerns the provision of supportive services to new or expecting parents who have received positive results of prenatal or postnatal testing for Down syndrome and other prenatally and postnataally diagnosed conditions.

The supportive services include, but are not be limited to:
• the establishment of a telephone hotline to provide information about available resources and services to a new or expecting parent receiving a positive result of a test for Down syndrome or other prenatally or postnatally diagnosed conditions;

• current information, posted on the official website of the Department of Health and Senior Services (DHSS), about available resources and services to a new or expecting parent receiving positive results of a test for Down syndrome or other prenatally or postnatally diagnosed conditions;

• the expansion and development, as appropriate, of local peer support programs that effectively serve a woman who receives a prenatal, positive diagnosis for Down syndrome or other prenatal conditions, or a parent of an infant with a postnatally diagnosed condition;

• the expansion and development, as appropriate, of networks of providers who provide a new or expecting parent with up-to-date information on the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes; and

• the establishment of an awareness and education program, which includes current evidence-based information relating to Down syndrome and other prenatally and postnatally diagnosed conditions, for health care professionals or their designees who provide the results of prenatal or postnatal testing for Down syndrome and other prenatally and postnatally diagnosed conditions to a new or expecting parent.

Under the provisions of the bill, the Commissioner of Health and Senior Services shall authorize and oversee activities including, but not limited to:

• the awarding of grants, contracts, or cooperative agreements to collect and synthesize information relating to Down syndrome and other prenatally or postnatally diagnosed conditions and the testing for these conditions, and to disseminate this information to providers of supportive services and health care professionals treating a new or expecting parent receiving a positive result of a test for Down syndrome or other prenatally or postnatally diagnosed conditions; and

• coordinating the provision of and access to the supportive services.

In awarding any grants or contracts or entering into any agreements, the commissioner is required to give priority to partnerships between health care groups and organizations that advocate for persons with a disability.

The bill also provides that upon receipt of a positive result of a test for Down syndrome or other prenatally or postnatally diagnosed
conditions, the health care professional, or his designee, must
provide a new or expecting parent with:

• 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;
• a referral to a provider of supportive services;
• contact information about peer support programs;
• information about registries of families willing to adopt
  newborns with Down syndrome or other prenatally or
  postnatally diagnosed conditions, and about links to adoption
  agencies willing to place babies with Down syndrome or
  other prenatally or postnatally diagnosed conditions with
  families willing to adopt, established pursuant to the federal
  "Prenatally and Postnatally Diagnosed Conditions Awareness
  Act," Pub.L.110-374; and
• information about the telephone hotline and website
  established under the bill.

Under the bill, the commissioner is required to: coordinate the
implementation of the bill with the federal "Prenatally and
Postnatally Diagnosed Conditions Awareness Act," Pub.L.110-374;
and seek federal funds for the purposes of the bill, but there shall be
no State funds appropriated to the department in Fiscal Year 2009
for the purposes of the bill.
The bill provides for rule making by the commissioner and has a
delayed effective date of 180 days following enactment.