

ASSEMBLY, No. 483

STATE OF NEW JERSEY

219th LEGISLATURE

PRE-FILED FOR INTRODUCTION IN THE 2020 SESSION

Sponsored by:

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District 25 (Morris and Somerset)

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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: 2/20/2020)

1 **AN ACT** concerning prenatally and postnatally diagnosed conditions
2 and supplementing Title 26 of the Revised Statutes.

3

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

6

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

10

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

20

21 3. As used in this act:

22 "Commissioner" means the Commissioner of Health and Senior
23 Services;

24 "Department" means the Department of Health and Senior
25 Services;

26 "Down syndrome" means a chromosomal disorder caused by an
27 error in cell division that results in the presence of an extra, whole,
28 or partial copy of chromosome 21;

29 "Health care professional" means an individual who, acting
30 within the scope of his State licensure or certification, provides
31 health care services;

32 "Postnatally diagnosed condition" means a health condition
33 identified by postnatal genetic testing or postnatal screening
34 procedures during the 12-month period beginning at birth;

35 "Postnatal test" means a diagnostic or screening test that is
36 offered to an individual from birth to one year of age and is
37 administered by a health care professional, based on medical
38 history, family or ethnic background, previous test results,
39 symptoms presented by a child, or other risk factors;

40 "Prenatally diagnosed condition" means a fetal health condition
41 identified by prenatal genetic testing or prenatal screening
42 procedures; and

43 "Prenatal test" means a diagnostic or screening test that is
44 offered to a pregnant woman seeking routine prenatal care and is
45 administered by a health care professional, based on medical
46 history, family or ethnic background, previous test results, or other
47 risk factors.

1 4. a. The commissioner shall authorize and oversee activities
2 including, but not limited to:

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

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

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

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

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

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

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

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

40 (5) the establishment of an awareness and education program,
41 which includes current evidence-based information relating to
42 Down syndrome and other prenatally and postnatally diagnosed
43 conditions, for health care professionals or their designees who
44 provide the results of prenatal or postnatal testing for Down
45 syndrome and other prenatally and postnatally diagnosed conditions
46 to a new or expecting parent.

- 1 • the establishment of a telephone hotline to provide
2 information about available resources and services to a new
3 or expecting parent receiving a positive result of a test for
4 Down syndrome or other prenatally or postnatally diagnosed
5 conditions;
- 6 • current information, posted on the official website of the
7 Department of Health and Senior Services (DHSS), about
8 available resources and services to a new or expecting parent
9 receiving positive results of a test for Down syndrome or
10 other prenatally or postnatally diagnosed conditions;
- 11 • the expansion and development, as appropriate, of local peer
12 support programs that effectively serve a woman who
13 receives a prenatal, positive diagnosis for Down syndrome or
14 other prenatal conditions, or a parent of an infant with a
15 postnatally diagnosed condition;
- 16 • the expansion and development, as appropriate, of networks
17 of providers who provide a new or expecting parent with up-
18 to-date information on the range of outcomes for individuals
19 living with the diagnosed condition, including physical,
20 developmental, educational, and psychosocial outcomes; and
- 21 • the establishment of an awareness and education program,
22 which includes current evidence-based information relating
23 to Down syndrome and other prenatally and postnatally
24 diagnosed conditions, for health care professionals or their
25 designees who provide the results of prenatal or postnatal
26 testing for Down syndrome and other prenatally and
27 postnatally diagnosed conditions to a new or expecting
28 parent.

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

- 32 • the awarding of grants, contracts, or cooperative agreements
33 to collect and synthesize information relating to Down
34 syndrome and other prenatally or postnatally diagnosed
35 conditions and the testing for these conditions, and to
36 disseminate this information to providers of supportive
37 services and health care professionals treating a new or
38 expecting parent receiving a positive result of a test for Down
39 syndrome or other prenatally or postnatally diagnosed
40 conditions; and
- 41 • coordinating the provision of and access to the supportive
42 services.

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

47 The bill also provides that upon receipt of a positive result of a
48 test for Down syndrome or other prenatally or postnatally diagnosed

1 conditions, the health care professional, or his designee, must
2 provide a new or expecting parent with:

- 3 • up-to-date, evidence-based, written information concerning
4 the range of outcomes for individuals living with the
5 diagnosed condition, including physical, developmental,
6 educational, and psychosocial outcomes;
- 7 • a referral to a provider of supportive services;
- 8 • contact information about peer support programs;
- 9 • information about registries of families willing to adopt
10 newborns with Down syndrome or other prenatally or
11 postnatally diagnosed conditions, and about links to adoption
12 agencies willing to place babies with Down syndrome or
13 other prenatally or postnatally diagnosed conditions with
14 families willing to adopt, established pursuant to the federal
15 "Prenatally and Postnatally Diagnosed Conditions Awareness
16 Act," Pub.L.110-374; and
- 17 • information about the telephone hotline and website
18 established under the bill.

19 Under the bill, the commissioner is required to: coordinate the
20 implementation of the bill with the federal "Prenatally and
21 Postnatally Diagnosed Conditions Awareness Act," Pub.L.110-374;
22 and seek federal funds for the purposes of the bill, but there shall be
23 no State funds appropriated to the department in Fiscal Year 2009
24 for the purposes of the bill.

25 The bill provides for rule making by the commissioner and has a
26 delayed effective date of 180 days following enactment.