

2019 Regular Session

HOUSE BILL NO. 143

BY REPRESENTATIVE WHITE

Prefiled pursuant to Article III, Section 2(A)(4)(b)(i) of the Constitution of Louisiana.

HEALTH/ANATOMICAL GIFTS: Provides for rights of qualified organ transplant candidates who have a disability

1 AN ACT

2 To enact R.S. 17:2353(M), R.S. 22:1023.1, and Subpart A-1 of Part IV of Subchapter A of

3 Chapter 5-D of Title 40 of the Louisiana Revised Statutes of 1950, to be comprised

4 of R.S. 40:1170.1 through 1170.4, relative to potential recipients of organ

5 transplants; to provide for rights of such persons; to prohibit discrimination against

6 such persons based on disability; to prohibit certain actions by health insurance

7 issuers with respect to organ transplantation; to authorize civil actions for relief in

8 cases of violations of the prohibition on discrimination in organ transplantation; to

9 require courts to follow certain procedures in considering such actions; to provide

10 for definitions; to provide for legislative findings; and to provide for related matters.

11 Be it enacted by the Legislature of Louisiana:

12 Section 1. R.S. 17:2353(M) is hereby enacted to read as follows:

13 §2353. Persons who may receive anatomical gifts; purpose of anatomical gifts

14 * * *

15 M. Potential anatomical gift recipients shall be entitled to the protections
16 against discrimination based on disability provided in R.S. 40:1170.1 et seq.

17 Section 2. R.S. 22:1023.1 is hereby enacted to read as follows:

1 §1023.1. Prohibited discrimination; potential organ transplant recipients with
2 disabilities

3 A. For purposes of this Section, the following terms have the meaning
4 ascribed to them in this Subsection:

5 (1) "Anatomical gift" means a donation of all or part of a human body that
6 takes effect after the death of the donor for the purpose of transplantation or
7 transfusion.

8 (2) "Covered person" means a policyholder, subscriber, enrollee, member,
9 or individual covered by a health benefit plan.

10 (3) "Disability" has the meaning ascribed in 42 U.S.C. 12102.

11 (4) "Health benefit plan" means a policy, contract, certificate, or agreement
12 entered into, offered, or issued by a health insurance issuer to provide, deliver,
13 arrange for, pay for, or reimburse any of the costs of healthcare services. "Health
14 benefit plan" shall not include a plan that provides coverage for excepted benefits as
15 defined in R.S. 22:1061 or short term policies that have a term of less than twelve
16 months.

17 (5) "Health insurance issuer" means an entity subject to the insurance laws
18 and regulations of this state, or subject to the jurisdiction of the commissioner, that
19 contracts or offers to contract to provide, deliver, arrange for, pay for, or reimburse
20 any of the costs of healthcare services, including through a health benefit plan as
21 defined in this Subsection, and shall include a sickness and accident insurance
22 company, a health maintenance organization, a preferred provider organization or
23 any similar entity, or any other entity providing a plan of health insurance or health
24 benefits.

25 (6) "Organ transplant" means the transplantation or transfusion of a part of
26 a human body into the body of another for the purpose of treating or curing a medical
27 condition.

28 B. A health insurance issuer that provides coverage for anatomical gifts,
29 organ transplants, or related treatment and services shall not do any of the following:

1 (1) Deny coverage to a covered person solely on the basis of the person
2 having a disability.

3 (2) Deny to a patient eligibility, or continued eligibility, to enroll or to renew
4 coverage under the terms of the health benefit plan, solely for the purpose of
5 avoiding the requirements of this Section.

6 (3) Penalize or otherwise reduce or limit the reimbursement of an attending
7 provider, or provide monetary or nonmonetary incentives to an attending provider,
8 to induce such provider to furnish care to an insured or enrollee in a manner
9 inconsistent with this Section.

10 (4) Reduce or limit coverage benefits to a patient for the medical services or
11 other services related to organ transplantation performed pursuant to this Section as
12 determined in consultation with the attending physician and patient.

13 C. In the case of a health benefit plan maintained pursuant to one or more
14 collective bargaining agreements between employee representatives and one or more
15 employers, any plan amendment made pursuant to a collective bargaining agreement
16 relating to the plan which amends the plan solely to conform to any requirement
17 imposed pursuant to this Section shall not be treated as a termination of the
18 collective bargaining agreement.

19 D. Nothing in this Section shall be construed as requiring a health insurance
20 issuer to provide coverage for a medically inappropriate organ transplant.

21 Section 3. Subpart A-1 of Part IV of Subchapter A of Chapter 5-D of Title 40 of the
22 Louisiana Revised Statutes of 1950, comprised of R.S. 40:1170.1 through 1170.4, is hereby
23 enacted to read as follows:

24 SUBPART A-1. ORGAN TRANSPLANTATION: RIGHT OF POTENTIAL

25 RECIPIENTS TO NONDISCRIMINATION

26 §1170.1. Legislative findings; declaration

27 A. The legislature hereby finds all of the following:

28 (1) A developmental, intellectual, or physical disability does not diminish
29 a person's right to health care.

1 (2) The provisions of the Americans with Disabilities Act of 1990, as
2 amended (42 U.S.C. 12101 et seq.), prohibit discrimination against persons with
3 disabilities, yet many individuals with disabilities experience discrimination in
4 accessing critical healthcare services.

5 (3) In some cases, persons with developmental, intellectual, or physical
6 disabilities have been denied life-saving organ transplants based on beliefs or
7 assumptions by healthcare providers that those persons are incapable of complying
8 with post-transplant medical requirements, or that they lack adequate support
9 systems to ensure compliance with those medical requirements.

10 (4) Although organ transplant centers must consider medical and
11 psychosocial criteria when determining whether a patient is suitable to receive an
12 organ transplant, transplant centers that participate in Medicare, Medicaid, and other
13 federally funded programs are required to use patient selection criteria that result in
14 a fair and nondiscriminatory distribution of organs.

15 B. The legislature hereby declares that Louisiana residents in need of organ
16 transplants shall be entitled to an assurance that they will not encounter
17 discrimination on the basis of a disability.

18 §1170.2. Definitions

19 For purposes of this Subpart, the following terms have the meaning ascribed
20 to them in this Section:

21 (1) "Anatomical gift" means a donation of all or part of a human body that
22 takes effect after the death of the donor for the purpose of transplantation or
23 transfusion.

24 (2) "Auxiliary aid or service" means an aid or service that is used to provide
25 information to an individual with a cognitive, developmental, intellectual,
26 neurological, or physical disability and is available in a format or manner that allows
27 the individual to better understand the information. An auxiliary aid or service may
28 include any of the following:

1 (a) Qualified interpreters or other effective methods of making aurally
2 delivered materials available to persons who are deaf or hard of hearing.

3 (b) Qualified readers, taped texts, texts in accessible electronic format, or
4 other effective methods of making visually delivered materials available to persons
5 with visual impairments.

6 (c) Supported decision-making services, including all of the following:

7 (i) The use of a support individual to communicate information to the person
8 with a disability, ascertain the wishes of the person, or assist the person in making
9 decisions.

10 (ii) The disclosure of information to a legal guardian, authorized
11 representative, or another individual designated by the person with a disability for
12 such purpose. A person making such disclosure shall do so in conformance with all
13 applicable requirements of state and federal law, including but not limited to those
14 of the Health Insurance Portability and Accountability Act of 1996 (42 U.S.C. 1320d
15 et seq.) and any federal regulations promulgated by the United States Department of
16 Health and Human Services for implementation of that law.

17 (iii) If an individual has a court-appointed guardian or other individual
18 responsible for making medical decisions on behalf of the individual, any measures
19 used to ensure that the individual is included in decisions involving the individual's
20 health care and that medical decisions are in accordance with the individual's own
21 expressed interests.

22 (iv) Any other aid or service that is used to provide information in a format
23 that is easily understandable and accessible to individuals with cognitive,
24 neurological, developmental or intellectual disabilities, including assistive
25 communication technology.

26 (3) "Covered entity" means any of the following entities:

27 (a) Any licensed provider of healthcare services, including licensed
28 healthcare practitioners, hospitals, nursing facilities, laboratories, intermediate care

1 facilities, psychiatric residential treatment facilities, institutions for individuals with
2 intellectual or developmental disabilities, and prison health centers.

3 (b) Any entity responsible for matching anatomical gift donors to potential
4 recipients.

5 (4) "Disability" has the meaning ascribed in 42 U.S.C. 12102.

6 (5) "Organ transplant" means the transplantation or transfusion of a part of
7 a human body into the body of another for the purpose of treating or curing a medical
8 condition.

9 (6)(a) "Qualified recipient" means an individual who has a disability and
10 meets the essential eligibility requirements for the receipt of an anatomical gift.

11 (b) An individual who has a disability and meets the essential eligibility
12 requirements for the receipt of an anatomical gift shall be deemed to be a qualified
13 recipient regardless of any of the following:

14 (i) Whether he has access to individuals or entities available to support and
15 assist him with an anatomical gift or transplantation.

16 (ii) Whether he has access to auxiliary aids or services.

17 (iii) Whether reasonable modifications to the policies, practices, or
18 procedures of a covered entity are implemented, including modifications to allow for
19 either of the following:

20 (aa) Communication with one or more individuals or entities available to
21 support or assist with the recipient's care and medication after surgery or
22 transplantation.

23 (bb) Consideration of support networks available to the individual, including
24 family, friends, and home- and community-based services, including home- and
25 community-based services funded through Medicaid, Medicare, another health plan
26 in which the individual is enrolled, or any program or source of funding available to
27 the individual, when determining whether the individual is able to comply with
28 post-transplant medical requirements.

1 §1170.3. Discrimination against potential organ transplant recipients based on
2 disability; prohibition

3 A. The provisions of this Section shall apply to all stages of the organ
4 transplant process.

5 B. It shall be unlawful for a covered entity to do any of the following solely
6 on the basis of an individual having a disability:

7 (1) Consider the individual ineligible to receive an anatomical gift or organ
8 transplant.

9 (2) Deny medical services or other services related to organ transplantation,
10 including diagnostic services, evaluation, surgery, counseling, and post-operative
11 treatment and services.

12 (3) Refuse to refer the individual to a transplant center or other related
13 specialist for the purpose of being evaluated for or receiving an organ transplant.

14 (4) Refuse to place a qualified recipient on an organ transplant waiting list.

15 (5) Place a qualified recipient on an organ transplant waiting list at a lower
16 priority position than the position at which the individual would have been placed
17 if the individual did not have a disability.

18 (6) Refuse insurance coverage for any procedure associated with being
19 evaluated for or receiving an anatomical gift or organ transplant, including
20 post-transplantation and post-transfusion care.

21 C. Notwithstanding the provisions of Subsection B of this Section, a covered
22 entity may consider an individual's disability when making treatment or coverage
23 recommendations or decisions, but only to the extent that the disability has been
24 found by a physician or surgeon, following an individualized evaluation of the
25 individual, to be medically significant to the provision of the anatomical gift.

26 D. If an individual has the necessary support system to assist him in
27 complying with post-transplant medical requirements, a covered entity may not
28 consider the individual's inability to independently comply with post-transplant

1 medical requirements to be medically significant for the purposes of Subsection C
2 of this Section.

3 E. A covered entity shall make reasonable modifications to its policies,
4 practices, or procedures to allow individuals with disabilities access to
5 transplantation-related services, including diagnostic services, surgery, coverage,
6 post-operative treatment, and counseling, unless the entity can demonstrate that
7 making such modifications would fundamentally alter the nature of such services.

8 F. A covered entity shall take all such actions as are necessary to ensure that
9 an individual with a disability is not denied medical services or other services related
10 to organ transplantation, including diagnostic services, surgery, post-operative
11 treatment, or counseling due to the absence of auxiliary aids or services, unless the
12 entity demonstrates that taking the actions would fundamentally alter the nature of
13 such services or would result in an undue burden for the entity.

14 G. Nothing in this Section shall be deemed to require a covered entity to
15 make a referral or recommendation for or to perform a medically inappropriate organ
16 transplant.

17 §1170.4. Enforcement; civil actions against covered entities; construction of Section

18 A. Whenever an individual believes that a covered entity has violated or is
19 violating any provision of R.S. 40:1170.3, the affected individual may commence a
20 civil action for injunctive and other equitable relief against the covered entity for
21 purposes of enforcing compliance with this Subpart. The action may be brought in
22 the district court for the parish where the affected individual resides or resided or
23 was denied the organ transplant or referral.

24 B. In an action brought under this Section, the court shall give the action
25 priority on its docket and expedited review, and may grant injunctive or other
26 equitable relief including by any of the following means:

27 (1) Requiring auxiliary aids or services to be made available for a qualified
28 recipient.

1 (2) Requiring the modification of a policy, practice, or procedure of a
2 covered entity.

3 (3) Requiring that facilities be made readily accessible to and usable by a
4 qualified recipient.

5 C. Nothing in this Section is intended to limit or replace available remedies
6 under the Americans with Disabilities Act of 1990, as amended (42 U.S.C. 12101 et
7 seq.), or any other applicable law.

8 D. This Section shall not be construed as creating a right to compensatory
9 or punitive damages against a covered entity.

10 Section 4.(A) The legislature hereby declares that the life of a person with a
11 disability who needs an organ transplant is as worthy and valuable as the life of a person
12 with no disability who needs the same medical service.

13 (B) This Act shall be known and may be cited as "Evie's Law".

14 Section 5. This Act shall become effective upon signature by the governor or, if not
15 signed by the governor, upon expiration of the time for bills to become law without signature
16 by the governor, as provided by Article III, Section 18 of the Constitution of Louisiana. If
17 vetoed by the governor and subsequently approved by the legislature, this Act shall become
18 effective on the day following such approval.

DIGEST

The digest printed below was prepared by House Legislative Services. It constitutes no part of the legislative instrument. The keyword, one-liner, abstract, and digest do not constitute part of the law or proof or indicia of legislative intent. [R.S. 1:13(B) and 24:177(E)]

HB 143 Original

2019 Regular Session

White

Abstract: Prohibits discrimination against potential organ transplant recipients based on disability.

Proposed law presents legislative findings relative to organ transplantation and discrimination against persons with developmental, intellectual, or physical disabilities. Declares that La. residents in need of organ transplants shall be entitled to an assurance that they will not encounter discrimination on the basis of a disability.

Proposed law provides the following definitions for purposes of proposed law:

- (1) "Auxiliary aid or service" means an aid or service that is used to provide information to an individual with a cognitive, developmental, intellectual, neurological, or physical disability and is available in a format or manner that allows the individual

- to better understand the information. Proposed law provides an illustrative list of auxiliary aids and services.
- (2) "Covered entity" means any of the following entities:
- (a) Any licensed provider of healthcare services, including licensed healthcare practitioners, hospitals, nursing facilities, laboratories, intermediate care facilities, psychiatric residential treatment facilities, institutions for individuals with intellectual or developmental disabilities, and prison health centers.
- (b) Any entity responsible for matching anatomical gift donors to potential recipients.
- (3) "Qualified recipient" means an individual who has a disability and meets the essential eligibility requirements for the receipt of an anatomical gift.

Proposed law provides that it shall be unlawful for a covered entity to do any of the following solely on the basis of an individual having a disability:

- (1) Consider the individual ineligible to receive an anatomical gift or organ transplant.
- (2) Deny medical services or other services related to organ transplantation, including diagnostic services, evaluation, surgery, counseling, and post-operative treatment and services.
- (3) Refuse to refer the individual to a transplant center or other related specialist for the purpose of being evaluated for or receiving an organ transplant.
- (4) Refuse to place a qualified recipient on an organ transplant waiting list.
- (5) Place a qualified recipient on an organ transplant waiting list at a lower priority position than the position at which the individual would have been placed if the individual did not have a disability.
- (6) Refuse insurance coverage for any procedure associated with being evaluated for or receiving an anatomical gift or organ transplant, including post-transplantation and post-transfusion care.

Proposed law provides that notwithstanding any provisions of proposed law to the contrary, a covered entity may consider an individual's disability when making treatment or coverage recommendations or decisions, but only to the extent that the disability has been found by a physician or surgeon, following an individualized evaluation of the individual, to be medically significant to the provision of the anatomical gift.

Proposed law stipulates that if an individual has the necessary support system to assist him in complying with post-transplant medical requirements, a covered entity may not consider the individual's inability to independently comply with post-transplant medical requirements to be medically significant for the purposes of proposed law.

Proposed law requires each covered entity to make reasonable modifications to its policies, practices, or procedures to allow individuals with disabilities access to transplantation-related services unless the entity can demonstrate that making such modifications would fundamentally alter the nature of such services.

Proposed law requires that each covered entity shall take all such actions as are necessary to ensure that an individual with a disability is not denied medical services or other services

related to organ transplantation due to the absence of auxiliary aids or services, except under either of the following conditions:

- (1) The entity demonstrates that taking the actions would fundamentally alter the nature of the medical services or other services related to organ transplantation.
- (2) The entity demonstrates that taking the actions would result in an undue burden for the covered entity.

Proposed law provides that nothing therein shall be deemed to require a covered entity to make a referral or recommendation for or to perform a medically inappropriate organ transplant.

Proposed law provides that whenever an individual believes a covered entity has violated the prohibition against discrimination established in proposed law, the affected individual may commence a civil action for injunctive and other equitable relief against the covered entity for purposes of enforcing compliance with proposed law. Provides that the action may be brought in the district court for the parish where the affected individual resides or resided or was denied the organ transplant or referral.

Proposed law requires that in actions brought pursuant to proposed law, courts shall give those actions priority on their dockets and expedited review. Authorizes courts to grant injunctive or other equitable relief, including by any of the following means:

- (1) Requiring auxiliary aids or services to be made available for a qualified recipient.
- (2) Requiring the modification of a policy, practice, or procedure of a covered entity.
- (3) Requiring that facilities be made readily accessible to and usable by a qualified recipient.

Proposed law stipulates that it is not intended to limit or replace available remedies under the Americans with Disabilities Act or any other applicable law. Stipulates further that proposed law shall not be construed as creating a right to compensatory or punitive damages against a covered entity.

Present law, R.S. 22:1021 et seq., provides relative to state-mandated health insurance benefits and nondiscrimination in health insurance coverage. Proposed law retains present law and adds thereto provisions prohibiting health insurance issuers that provide coverage for anatomical gifts, organ transplants, or related treatment and services from doing any of the following:

- (1) Deny coverage to a covered person solely on the basis of the person having a disability.
- (2) Deny to a patient eligibility, or continued eligibility, to enroll or to renew coverage under the terms of the health benefit plan, solely for the purpose of avoiding the requirements of this Section.
- (3) Penalize or otherwise reduce or limit the reimbursement of an attending provider, or provide monetary or nonmonetary incentives to an attending provider, to induce such provider to furnish care to an insured or enrollee in a manner inconsistent with this Section.
- (4) Reduce or limit coverage benefits to a patient for the medical services or other services related to organ transplantation performed pursuant to this Section as determined in consultation with the attending physician and patient.

Proposed law stipulates that in the case of a health benefit plan maintained pursuant to a collective bargaining agreement between employee representatives and one or more employers, any plan amendment made solely to conform to a requirement of proposed law shall not be treated as a termination of the collective bargaining agreement.

Proposed law provides that nothing therein shall be construed as requiring a health insurance issuer to provide coverage for a medically inappropriate organ transplant.

Proposed law, R.S. 17:2351 et seq., establishes the Anatomical Gift Act governing the donation, procurement, receipt, and uses of anatomical gifts in La. Proposed law retains present law and adds thereto an affirmation that potential anatomical gift recipients shall be entitled to the protections against discrimination based on disability provided in proposed law.

Proposed law provides that it shall be known and may be cited as "Evie's Law".

Effective upon signature of governor or lapse of time for gubernatorial action.

(Adds R.S. 17:2353(M), R.S. 22:1023.1, and R.S. 40:1170.1-1170.4)