

2021 -- H 6079

LC002281

STATE OF RHODE ISLAND

IN GENERAL ASSEMBLY

JANUARY SESSION, A.D. 2021

A N A C T

RELATING TO HEALTH AND SAFETY – NONDISCRIMINATION IN ACCESS TO ANATOMICAL GIFTS AND ORGAN TRANSPLANT ACT (ISAAC'S LAW)

Introduced By: Representatives Giraldo, Alzate, Potter, Morales, Barros, Diaz, Baginski, Tobon, and McGaw

Date Introduced: March 03, 2021

Referred To: House Health & Human Services

It is enacted by the General Assembly as follows:

1 SECTION 1. Legislative Findings and Declaration.

2 The general assembly finds and declares that:

3 (1) A mental or physical disability does not diminish a person's right to health care;

4 (2) The "Americans with Disabilities Act of 1990", 42 U.S.C. § 12101, prohibits
5 discrimination against persons with disabilities, yet many individuals with disabilities still
6 experience discrimination in accessing critical health care services;

7 (3) Nationwide, individuals with mental and physical disabilities have been denied life-
8 saving organ transplants based on assumptions that their lives are less worthy, that they are
9 incapable of complying with post-transplant medical requirements, or that they lack adequate
10 support systems to ensure compliance with post-transplant medical requirements;

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

15 (5) Rhode Island residents in need of organ transplants are entitled to assurances that they
16 will not encounter discrimination on the basis of a disability.

17 SECTION 2. Title 23 of the General Laws entitled "HEALTH AND SAFETY" is hereby
18 amended by adding thereto the following chapter:

1 CHAPTER 95

2 NONDISCRIMINATION IN ACCESS TO ANATOMICAL GIFTS AND ORGAN

3 TRANSPLANT ACT (ISAAC'S LAW)

4 **23-95-1. Short title.**

5 This chapter shall be known and may be cited as the "Nondiscrimination in Access to
6 Anatomical Gifts and Organ Transplants Act (Isaac's Law)".

7 **23-95-2. Legislative purpose.**

8 It is the purpose of this chapter to prohibit discrimination against a potential organ
9 transplant recipient based solely on a person's physical or mental disability.

10 **23-95-3. Definitions.**

11 As used in this chapter, the following words and terms shall have the following meanings
12 unless the context shall clearly indicate another or different meaning or intent:

13 (1) "Anatomical gift" means a donation of all or part of a human body to take effect after
14 the donor's death for the purpose of transplantation or transfusion.

15 (2) "Auxiliary aids or services" means an aid or service that is used to provide information
16 to an individual with a cognitive, developmental, intellectual, neurological, or physical disability
17 and is available in a format or manner that allows the individual to better understand the
18 information. An auxiliary aid or service may include:

19 (i) Qualified interpreters or other effective methods of making aurally delivered materials
20 available to persons with hearing impairments;

21 (ii) Qualified readers, taped texts, texts in accessible electronic format, or other effective
22 methods of making visually delivered materials available to persons with visual impairments;

23 (iii) Supported decision-making services, including:

24 (A) The use of a support individual to communicate information to the individual with a
25 disability, ascertain the wishes of the individual, or assist the individual in making decisions;

26 (B) The disclosure of information to a legal guardian, authorized representative, or another
27 individual designated by the individual with a disability for such purpose, as long as the disclosure
28 is consistent with state and federal law, including the federal "Health Insurance Portability and
29 Accountability Act of 1996," 42 U.S.C. 1320d et seq., and any regulations promulgated by the
30 United States Department of Health and Human Services to implement the act;

31 (C) If an individual has a court-appointed guardian or other individual responsible for
32 making medical decisions on behalf of the individual, any measures used to ensure that the
33 individual is included in decisions involving the individual's health care and that medical decisions
34 are in accordance with the individual's own expressed interests;

1 (D) Any other aid or service that is used to provide information in a format that is easily
2 understandable and accessible to individuals with cognitive, neurological, developmental or
3 intellectual disabilities, including assistive communication technology.

4 (3) "Covered entity" means:

5 (i) Any licensed provider of health care services, including licensed health care
6 practitioners, hospitals, nursing facilities, laboratories, intermediate care facilities, psychiatric
7 residential treatment facilities, institutions for individuals with intellectual or developmental
8 disabilities, and prison health centers;

9 (ii) Any entity responsible for matching anatomical gift donors to potential recipients.

10 (4) "Disability" means a disability as defined in § 42-87-1 in accordance with the
11 Americans with Disabilities Act of 1990, as amended by the ADA Amendments Act of 2008, at 42
12 U.S.C. § 12102.

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

15 (6) "Qualified recipient" means an individual who has a disability and meets the essential
16 eligibility requirements for the receipt of an anatomical gift with or without any of the following:

17 (i) Individuals or entities available to support and assist the individual with an anatomical
18 gift or transplantation;

19 (ii) Auxiliary aids or services;

20 (iii) Reasonable modifications to the policies, practices, or procedures of a covered entity,
21 including modifications to allow for either or both of the following:

22 (A) Communication with one or more individuals or entities available to support or assist
23 with the recipient's care and medication after surgery or transplantation;

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

29 **23-95-4. Discrimination prohibited.**

30 (a) The provisions of this chapter shall apply to all stages of the organ transplant process.

31 (b) A covered entity shall not, solely on the basis of an individual's disability:

32 (1) Consider the individual ineligible to receive an anatomical gift or organ transplant;

33 (2) Deny medical services or other services related to organ transplantation, including
34 diagnostic services, evaluation, surgery, counseling, post-operative treatment and services;

1 (3) Refuse to refer the individual to a transplant center or other related specialist for the
2 purpose of being evaluated for or receiving an organ transplant;

3 (4) Refuse to place a qualified recipient on an organ transplant waiting list;

4 (5) Place a qualified recipient on an organ transplant waiting list at a lower priority position
5 than the position at which the individual would have been placed if the individual did not have a
6 disability; or,

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

10 (c) Notwithstanding subsection (b) of this section, a covered entity may take an individual's
11 disability into account when making treatment or coverage recommendations or decisions, solely
12 to the extent that the disability has been found by a physician or surgeon, following personalized
13 evaluation of the individual, to be medically significant to the provision of the anatomical gift.

14 (d) If an individual has the necessary support system to assist the individual in complying
15 with post-transplant medical requirements, a covered entity may not consider the individual's
16 inability to independently comply with post-transplant medical requirements to be medically
17 significant for the purposes of subsection (c) of this section.

18 (e) A covered entity must make reasonable modifications to its policies, practices, or
19 procedures to allow individuals with disabilities access to transplantation-related services,
20 including diagnostic services, surgery, coverage, post-operative treatment, and counseling, unless
21 the entity can demonstrate that making such modifications would fundamentally alter the nature of
22 such services.

23 (f) A covered entity must take steps necessary to ensure that an individual with a disability
24 is not denied medical services or other services related to organ transplantation, including
25 diagnostic services, surgery, post-operative treatment, or counseling, due to the absence of auxiliary
26 aids or services, unless the covered entity demonstrates that taking the steps would fundamentally
27 alter the nature of the medical services or other services related to organ transplantation or would
28 result in an undue burden for the covered entity.

29 (g) Nothing in this section shall be deemed to require a covered entity to make a referral or
30 recommendation for or perform a medically inappropriate organ transplant.

31 (h) A covered entity shall otherwise comply with the requirements of Titles II and III of
32 the Americans with Disabilities Act of 1990, as amended by the ADA Amendments Act of 2008.

33 **23-95-5. Enforcement.**

34 (a) Whenever it appears that a covered entity has violated or is violating any of the

1 provisions of this chapter, the affected individual may commence a civil action for injunctive and
2 other equitable relief against the covered entity for purposes of enforcing compliance with this
3 chapter. The action may be brought in the district court for the county where the affected individual
4 resides or resided or was denied the organ transplant or referral.

5 (b) In an action brought under this chapter, the court must give priority on its docket and
6 expedited review, and may grant injunctive or other equitable relief, including:

7 (1) Requiring auxiliary aids or services to be made available for a qualified recipient;

8 (2) Requiring the modification of a policy, practice or procedure of a covered entity; or,

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

10 (c) Nothing in this chapter is intended to limit or replace available remedies under the
11 Americans with Disabilities Act of 1990, as amended by the ADA Amendments Act of 2008 or
12 any other applicable law.

13 (d) This chapter does not create a right to compensatory or punitive damages against a
14 covered entity.

15 **23-95-6. Insurance.**

16 (a) As used in this section, the following words and terms shall have the following
17 meanings:

18 (1) "Covered person" means a policyholder, subscriber, enrollee, member, or individual
19 covered by a health benefit plan.

20 (2) "Health benefit plan" means a policy, contract, certificate, or agreement entered into,
21 offered, or issued by a health insurer to provide, deliver, arrange for, pay for, or reimburse any of
22 the costs of health care services. "Health benefit plan" shall not include a plan providing coverage
23 for excepted benefits and short-term policies that have a term of less than twelve (12) months.

24 (3) "Health insurer" means an entity subject to the insurance laws and regulations of this
25 state, or subject to the jurisdiction of the Rhode Island health insurance commissioner, that
26 contracts or offers to contract to provide, deliver, arrange for, pay for, or reimburse any of the costs
27 of health care services, including through a health benefit plan as defined in this section, and shall
28 include a sickness and accident insurance company, a health maintenance organization, a preferred
29 provider organization, or any similar entity, or any other entity providing a plan of health insurance
30 or health benefits.

31 (b) A health insurer that provides coverage for anatomical gifts, organ transplants, or
32 related treatment and services shall not:

33 (1) Deny coverage to a covered person solely on the basis of the person's disability;

34 (2) Deny to a patient eligibility, or continued eligibility, to enroll or to renew coverage

1 under the terms of the health benefit plan, solely for the purpose of avoiding the requirements of
2 this section;

3 (3) Penalize or otherwise reduce or limit the reimbursement of an attending provider, or
4 provide monetary or nonmonetary incentives to an attending provider, to induce such provider to
5 provide care to an insured or enrollee in a manner inconsistent with this section; or,

6 (4) Reduce or limit coverage benefits to a patient for the medical services or other services
7 related to organ transplantation performed pursuant to this section as determined in consultation
8 with the attending physician and patient.

9 (c) In the case of a health benefit plan maintained pursuant to one or more collective
10 bargaining agreements between employee representatives and one or more employers, any plan
11 amendment made pursuant to a collective bargaining agreement relating to the plan which amends
12 the plan solely to conform to any requirement imposed pursuant to this section shall not be treated
13 as a termination of the collective bargaining agreement.

14 (d) Nothing in this section shall be deemed to require a health insurer to provide coverage
15 for a medically inappropriate organ transplant.

16 **23-95-7. Severability.**

17 If any clause, sentence, paragraph, section, or part of this chapter shall be adjudged by any
18 court of competent jurisdiction to be invalid, that judgment shall not affect, impair, or invalidate
19 the remainder of the chapter but shall be confined in its operation to the clause, sentence, paragraph,
20 section, or part directly involved in the controversy in which that judgment shall have been
21 rendered.

22 SECTION 3. Chapter 27-18 of the General Laws entitled "Accident and Sickness Insurance
23 Policies" is hereby amended by adding thereto the following section:

24 **27-18-85. Prohibition on discrimination in organ transplants.**

25 Pursuant to chapter 95 of title 23, any health insurer that provides coverage for anatomical
26 gifts, organ transplants, or related treatment and services shall not:

27 (1) Deny coverage to a covered person solely on the basis of the person's disability;

28 (2) Deny to a patient eligibility, or continued eligibility, to enroll or to renew coverage
29 under the terms of the health benefit plan, solely for the purpose of avoiding the requirements of
30 this section;

31 (3) Penalize or otherwise reduce or limit the reimbursement of an attending provider, or
32 provide monetary or nonmonetary incentives to an attending provider, to induce such provider to
33 provide care to an insured or enrollee in a manner inconsistent with this section; or

34 (4) Reduce or limit coverage benefits to a patient for the medical services or other services

1 related to organ transplantation performed pursuant to this section as determined in consultation
2 with the attending physician and patient.

3 SECTION 4. Chapter 27-19 of the General Laws entitled "Nonprofit Hospital Service
4 Corporations" is hereby amended by adding thereto the following section:

5 **27-19-77. Prohibition on discrimination in organ transplants.**

6 Pursuant to chapter 95 of title 23, any nonprofit hospital that provides for anatomical gifts,
7 organ transplants, or related treatment and services shall not:

8 (1) Deny coverage to a covered person solely on the basis of the person's disability;

9 (2) Deny to a patient eligibility, or continued eligibility, to enroll or to renew coverage
10 under the terms of the health benefit plan, solely for the purpose of avoiding the requirements of
11 this section;

12 (3) Penalize or otherwise reduce or limit the reimbursement of an attending provider, or
13 provide monetary or nonmonetary incentives to an attending provider, to induce such provider to
14 provide care to an insured or enrollee in a manner inconsistent with this section; or

15 (4) Reduce or limit coverage benefits to a patient for the medical services or other services
16 related to organ transplantation performed pursuant to this section as determined in consultation
17 with the attending physician and patient.

18 SECTION 5. Chapter 27-20 of the General Laws entitled "Nonprofit Medical Service
19 Corporations" is hereby amended by adding thereto the following section:

20 **27-20-73. Prohibition on discrimination in organ transplants.**

21 Pursuant to chapter 95 of title 23, any nonprofit medical service corporation that provides
22 for anatomical gifts, organ transplants, or related treatment and services shall not:

23 (1) Deny coverage to a covered person solely on the basis of the person's disability;

24 (2) Deny to a patient eligibility, or continued eligibility, to enroll or to renew coverage
25 under the terms of the health benefit plan, solely for the purpose of avoiding the requirements of
26 this section;

27 (3) Penalize or otherwise reduce or limit the reimbursement of an attending provider, or
28 provide monetary or nonmonetary incentives to an attending provider, to induce such provider to
29 provide care to an insured or enrollee in a manner inconsistent with this section; or

30 (4) Reduce or limit coverage benefits to a patient for the medical services or other services
31 related to organ transplantation performed pursuant to this section as determined in consultation
32 with the attending physician and patient.

33 SECTION 6. Chapter 27-41 of the General Laws entitled "Health Maintenance
34 Organizations" is hereby amended by adding thereto the following section:

1 **27-41-90. Prohibition on discrimination in organ transplants.**

2 Pursuant to chapter 95 of title 23, any nonprofit medical service corporation that provides
3 coverage for anatomical gifts, organ transplants, or related treatment and services shall not:

4 (1) Deny coverage to a covered person solely on the basis of the person’s disability;

5 (2) Deny to a patient eligibility, or continued eligibility, to enroll or to renew coverage
6 under the terms of the health benefit plan, solely for the purpose of avoiding the requirements of
7 this section;

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

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

14 SECTION 7. This act shall take effect upon passage.

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EXPLANATION
BY THE LEGISLATIVE COUNCIL
OF

A N A C T

RELATING TO HEALTH AND SAFETY – NONDISCRIMINATION IN ACCESS TO
ANATOMICAL GIFTS AND ORGAN TRANSPLANT ACT (ISAAC'S LAW)

1 This act would prohibit discrimination against a potential organ transplant recipient based
2 solely on a physical or mental disability. Specifically, an individual who is a candidate to receive
3 an anatomical gift would not be deemed ineligible or denied insurance coverage solely based on
4 the individual's physical or mental disability, except to the extent that the physical or mental
5 disability has been found by a physician or surgeon to be medically significant to the provision of
6 the anatomical gift.

7 This act would take effect upon passage.

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