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4

As Engrossed: S1/21/21 S2/3/21

A Bill

SENATE BILL 155

5 By: Senators B. Davis, T. Garner
6 By: Representatives McCollum, Pilkington, *Cloud, Ladyman, Scott, Haak, Vaught*
7

For An Act To Be Entitled

9 AN ACT TO ESTABLISH LILA’S LAW; TO PROHIBIT
10 DISCRIMINATION AGAINST INDIVIDUALS WITH DISABILITIES
11 REGARDING ACCESS TO ORGAN TRANSPLANTATION; TO REQUIRE
12 COVERED ENTITIES TO MAKE REASONABLE MODIFICATIONS TO
13 POLICIES, PRACTICES, AND PROCEDURES; TO PROVIDE
14 AUXILIARY AIDS AND SERVICES DURING THE ORGAN
15 TRANSPLANTATION PROCESS; AND FOR OTHER PURPOSES.
16

Subtitle

17
18 TO ESTABLISH LILA’S LAW; AND TO PROHIBIT
19 DISCRIMINATION AGAINST INDIVIDUALS WITH
20 DISABILITIES REGARDING ACCESS TO ORGAN
21 TRANSPLANTATION.
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25 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF ARKANSAS:
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27 SECTION 1. DO NOT CODIFY. Title.
28 This act shall be known and may be cited as "Lila’s Law".
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30 SECTION 2. Arkansas Code Title 20, Chapter 14, is amended to add an
31 additional subchapter to read as follows:

32 Subchapter 9 – Nondiscrimination in Access to Organ Transplantation
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34 20-14-901. Legislative intent.

35 The General Assembly finds that:

36 (1) A mental or physical disability does not diminish an



1 individual's right to health care;

2 (2) The Americans with Disabilities Act of 1990, 42 U.S.C. §
3 12101 et. seq., prohibits discrimination against individuals with
4 disabilities, yet many individuals with disabilities still experience
5 discrimination in accessing critical healthcare services;

6 (3) Individuals with disabilities have historically been denied
7 lifesaving organ transplants based on assumptions that their lives are less
8 worthy, that they are incapable of complying with post-transplant medical
9 regimens, or that they lack adequate support systems to ensure compliance;

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

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

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20 20-14-902. Definitions.

21 As used in this subchapter:

22 (1) "Anatomical gift" means a donation of all or part of a
23 donor's body after his or her death for transplantation or transfusion
24 purposes;

25 (2) "Auxiliary aids and services" includes without limitation:

26 (A) Qualified interpreters and other effective methods of
27 making aurally delivered materials available to individuals with hearing
28 impairments;

29 (B) Qualified readers, taped texts, and other effective
30 methods of making visually delivered materials available to individuals with
31 visual impairments;

32 (C) The provision of information in an accessible format
33 for individuals with cognitive, neurological, developmental, or intellectual
34 disabilities;

35 (D) The provision of supported decision-making services;

36 (E) The acquisition or modification of equipment or

1 devices; and

2 (F) Other similar services and actions;

3 (3) "Covered entity" means:

4 (A) A licensed provider of healthcare services, including
5 without limitation licensed healthcare practitioners, hospitals, nursing
6 facilities, laboratories, intermediate care facilities, psychiatric
7 residential treatment facilities, institutions for individuals with
8 intellectual or developmental disabilities, and prison health centers; and

9 (B) An entity responsible for matching anatomical gift or
10 organ donors to potential recipients;

11 (4) "Disability" means the same as stated in 42 U.S.C. § 12102,
12 as it existed on January 1, 2021;

13 (5) "Organ transplant" means the transplantation or transfusion
14 of a part of a human body into another human body to treat or cure a medical
15 condition;

16 (6) "Qualified individual" means an individual who:

17 (A) Has a disability; and

18 (B) Meets the essential eligibility requirements for the
19 receipt of an anatomical gift or organ transplant with or without:

20 (i) Support networks available to the individual;

21 (ii) The provision of auxiliary aids and services;

22 and

23 (iii) Reasonable modifications to policies,
24 practices, or procedures of a covered entity;

25 (7) "Reasonable modification" means:

26 (A) Communication with individuals responsible for
27 supporting a qualified individual with post-surgical and post-transplantation
28 care, including without limitation the administration of medication; and

29 (B) Consideration of support networks available to a
30 qualified individual to determine the qualified individual's ability to
31 comply with post-transplant medical requirements, including without
32 limitation consideration of:

33 (i) Family, friends, and home- and community-based
34 services funded through Medicaid, Medicare, or an other healthcare plan; and

35 (ii) Any program or source of funding available to
36 the qualified individual; and

1 (8) “Supported decision-making” means the use of a support
2 person to:

3 (A) Assist a qualified individual in making medical
4 decisions;

5 (B) Communicate information to a qualified individual;

6 (C) Ascertain a qualified individual’s wishes, including
7 without limitation:

8 (i) Including the qualified individual’s attorney-
9 in-fact, healthcare proxy, or any person of the qualified individual’s choice
10 in communications about his or her medical care;

11 (ii) Permitting the qualified individual access to a
12 person of his or her choice for support in communicating, processing
13 information, or making medical decisions;

14 (iii) Providing auxiliary aids and services to
15 facilitate the qualified individual’s ability to communicate and process
16 health-related information, including without limitation the use of assistive
17 technology;

18 (iv) Providing information to persons designated by
19 the qualified individual, consistent with the provisions of the Health
20 Insurance Portability and Accountability Act of 1996, 42 U.S.C. § 1301 et
21 seq., as it existed on January 1, 2021, and other applicable laws and
22 regulations governing disclosure of health information;

23 (v) Providing health information in a format that is
24 readily understandable by the qualified individual; and

25 (vi) Ensuring that the qualified individual is
26 included in decisions involving his or her own health care and that medical
27 decisions are in accordance with the qualified individual’s own expressed
28 interests when he or she has a court-appointed guardian or other individual
29 responsible for medical decisions on his or her behalf; or

30 (D) Any combination of the activities described in
31 subdivisions (8)(A)-(C) of this section.

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33 20-14-903. Discrimination prohibited.

34 (a) A covered entity shall not do any of the following based solely on
35 a qualified individual’s mental or physical disability:

36 (1) Determine that a qualified individual is ineligible to

1 receive an anatomical gift or organ transplant;

2 (2) Deny medical or other services related to an anatomical gift
3 or organ transplant, including without limitation evaluation, surgery,
4 counseling, or post-operative treatment and services;

5 (3) Refuse to refer a qualified individual to a transplant
6 center or other related specialist for the purpose of evaluation or receipt
7 of an anatomical gift or organ transplant;

8 (4) Refuse to place a qualified individual on an anatomical gift
9 or organ transplant waiting list;

10 (5) Place a qualified individual at a lower priority position on
11 an anatomical gift or organ transplant waiting list rather than the position
12 at which he or she would have been placed if not for his or her disability;
13 or

14 (6) Decline insurance coverage for a procedure associated with
15 the receipt of the anatomical gift or an organ transplant, including without
16 limitation post-transplantation care.

17 (b)(1) A covered entity may take a qualified individual's disability
18 into account when making treatment or coverage recommendations or decisions
19 only when the physician or surgeon:

20 (A) Conducts an individualized evaluation of the qualified
21 individual; and

22 (B) Finds the physical or mental disability of the
23 qualified individual to be medically significant to the provision of the
24 anatomical gift or organ transplant.

25 (2) A qualified individual's inability to independently comply
26 with post-transplant medical requirements is not medically significant if the
27 qualified individual has the necessary support network to assist him or her
28 in complying with the requirements.

29 (c) This section does not require the referral, recommendation, or
30 performance of a medically inappropriate organ transplant.

31 (d) A covered entity shall:

32 (1) Make reasonable modifications in policies, practices, and
33 procedures when necessary to make services, including without limitation
34 transplantation-related counseling, information, coverage, and treatment,
35 available to qualified individuals unless the covered entity demonstrates
36 that making the reasonable modifications would fundamentally alter the nature

1 of the services or would result in an undue burden;

2 (2) Ensure that a qualified individual is not denied services,
3 including without limitation transplantation-related counseling, information,
4 coverage, or treatment, because of the absence of auxiliary aids and services
5 unless the covered entity demonstrates that providing auxiliary aids and
6 services would fundamentally alter the nature of the services being offered
7 or would result in an undue burden; and

8 (3) Comply with the requirements of Titles II and III of the
9 Americans with Disabilities Act of 1990, 42 U.S.C. § 12101 et seq., as it
10 existed on January 1, 2021.

11 (e) This section applies to each part of the organ transplantation
12 process.

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14 20-14-904. Remedies.

15 (a) A qualified individual alleging a violation of this subchapter may
16 bring an action in the appropriate circuit court for injunctive or other
17 equitable relief.

18 (b) Unless otherwise prohibited by Arkansas Constitution, Amendment
19 80, the court shall:

20 (1) Schedule a hearing as soon as possible; and

21 (2) Proceed expeditiously with an action alleging a violation of
22 this subchapter.

23 (c) This section does not limit or replace remedies available under
24 the Americans with Disabilities Act of 1990, 42 U.S.C. § 12101 et seq., or
25 any other applicable law.

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28 */s/B. Davis*
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