

1 State of Arkansas As Engrossed: S1/21/21 S2/3/21 H3/8/21

2 93rd General Assembly

# A Bill

3 Regular Session, 2021

SENATE BILL 155

4

5 By: Senators B. Davis, T. Garner

6 By: Representatives McCollum, Pilkington, *Cloud, Ladyman, Scott, Haak, Vaught, Brooks, Ennett*

7

8

## 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

17

18

## Subtitle

19 TO ESTABLISH LILA'S LAW; AND TO PROHIBIT  
20 DISCRIMINATION AGAINST INDIVIDUALS WITH  
21 DISABILITIES REGARDING ACCESS TO ORGAN  
22 TRANSPLANTATION.

23

24

25 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF ARKANSAS:

26

27 SECTION 1. DO NOT CODIFY. Title.

28 This act shall be known and may be cited as "Lila's Law".

29

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

33

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.

19  
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.

32  
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.

13  
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.

26  
27  
28 */s/B. Davis*

29  
30  
31 **APPROVED: 4/22/21**