

Stricken language would be deleted from and underlined language would be added to present law.
Act 837 of the Regular Session

State of Arkansas *As Engrossed: S1/21/21 S2/3/21 H3/8/21*
93rd General Assembly **A Bill**
Regular Session, 2021

SENATE BILL 155

By: Senators B. Davis, T. Garner

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

For An Act To Be Entitled

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

Subtitle

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

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

SECTION 1. DO NOT CODIFY. Title.

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

SECTION 2. Arkansas Code Title 20, Chapter 14, is amended to add an
additional subchapter to read as follows:

Subchapter 9 – Nondiscrimination in Access to Organ Transplantation

20-14-901. Legislative intent.

The General Assembly finds that:

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



individual's right to health care;

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

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

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

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

20-14-902. Definitions.

As used in this subchapter:

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

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

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

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

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

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

(E) The acquisition or modification of equipment or

devices; and

(F) Other similar services and actions;

(3) "Covered entity" means:

(A) A licensed provider of healthcare services, including without limitation 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; and

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

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

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

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

(A) Has a disability; and

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

(i) Support networks available to the individual;

(ii) The provision of auxiliary aids and services;

and

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

(7) "Reasonable modification" means:

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

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

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

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

(8) "Supported decision-making" means the use of a support person to:

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

(B) Communicate information to a qualified individual;

(C) Ascertain a qualified individual's wishes, including without limitation:

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

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

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

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

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

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

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

20-14-903. Discrimination prohibited.

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

(1) Determine that a qualified individual is ineligible to

receive an anatomical gift or organ transplant;

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

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

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

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

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

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

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

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

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

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

(d) A covered entity shall:

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

of the services or would result in an undue burden;

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

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

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

20-14-904. Remedies.

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

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

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

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

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

/s/B. Davis

APPROVED: 4/22/21