

1 SB225
2 205436-1
3 By Senator Price
4 RFD: Healthcare
5 First Read: 20-FEB-20

2
3
4
5
6
7
8 SYNOPSIS: This bill would prohibit discrimination
9 against an individual from receiving an organ
10 transplant based on the individual having a
11 disability.

12 This bill would also require health care
13 practitioners, hospitals and other health care
14 facilities, and organ transplant centers to provide
15 reasonable accommodations to an individual with a
16 disability in medical need of an anatomical gift or
17 organ transplant.

18
19 A BILL
20 TO BE ENTITLED
21 AN ACT
22

23 Relating to health care; to prohibit discrimination
24 against an individual with a disability in receiving an
25 anatomical gift or organ transplant based on his or her
26 disability; and to require health care providers and organ
27 transplant centers to provide reasonable accommodations to

1 individuals with a disability in medical need of an anatomical
2 gift or organ transplant.

3 BE IT ENACTED BY THE LEGISLATURE OF ALABAMA:

4 Section 1. This act shall be known and may be cited
5 as Exton's Law.

6 Section 2. The Legislature finds all of the
7 following:

8 (1) A mental or physical disability does not
9 diminish an individual's right to health care.

10 (2) The Americans with Disabilities Act of 1990
11 prohibits discrimination against persons with disabilities,
12 yet many individuals with disabilities still experience
13 discrimination in accessing critical health care services.

14 (3) Historically, individuals with mental and
15 physical disabilities have been denied life-saving organ
16 transplants based on assumptions that their lives are less
17 worthy, that they are incapable of complying with
18 post-transplant medical regimens, or that they lack adequate
19 support systems to ensure compliance.

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

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

4 Section 3. As used in this act, the following terms
5 have the following meanings:

6 (1) ANATOMICAL GIFT. The donation of all or part of
7 a human body to take effect after the donor's death for the
8 purpose of transplantation or transfusion.

9 (2) AUXILIARY AIDS AND SERVICES. Includes all of the
10 following:

11 a. Qualified interpreters or other effective methods
12 of making aurally delivered materials available to individuals
13 with hearing impairments.

14 b. Qualified readers, taped texts, or other
15 effective methods of making visually delivered material
16 available to individuals with visual impairments.

17 c. Provision of supported decision making services,
18 including, but not limited to, all of the following:

19 1. The use of a support individual to assist in
20 making medical decisions, communicating information to the
21 individual, or ascertaining an individual's wishes.

22 2. The provision of information to an individual
23 designated by the individual, consistent with the federal
24 Health Insurance Portability and Accountability Act of 1996
25 and other applicable laws, rules, and regulations governing
26 the disclosure of health information.

1 3. If an individual has a court-appointed guardian
2 or other individual responsible for making medical decisions
3 on behalf of the individual, any measures used to ensure that
4 the individual is included in decisions involving the
5 individual's health care and that medical decisions are in
6 accordance with the individual's own expressed interests.

7 d. Acquisition or modification of equipment or
8 devices.

9 e. Any other aid or service that is used to provide
10 information in a format that is easily understandable and
11 accessible to individuals with cognitive, neurological,
12 developmental, or intellectual disabilities.

13 (3) COVERED ENTITY. Any of the following:

14 a. A health care provider licensed under Title 34,
15 Code of Alabama 1975.

16 b. A health care facility licensed under Chapter 21
17 of Title 22, Code of Alabama 1975.

18 c. An entity responsible for matching anatomical
19 gift donors to potential recipients.

20 (4) DISABILITY. The definition as provided in 42
21 U.S.C. § 12102.

22 (5) ORGAN TRANSPLANT. The transplantation or
23 transfusion of a part of a human body into the body of another
24 for the purpose of treating or curing a medical condition.

25 (6) QUALIFIED INDIVIDUAL. An individual with a
26 disability who meets the essential eligibility requirements

1 for the receipt of an anatomical gift, with or without any of
2 the following:

- 3 a. The support networks available to the individual.
- 4 b. The provision of auxiliary aids and services.
- 5 c. Reasonable modifications to the policies or
6 practices of a covered entity, including modifications to
7 allow both of the following:

- 8 1. Communication with individuals responsible for
9 supporting the individual with post-surgical and
10 post-transplantation care, including medication.

- 11 2. The consideration of support networks available
12 to the individual, including family, friends, and home- and
13 community-based services funded through Medicaid, Medicare, or
14 another health plan in which the individual is enrolled, or
15 any program or source of funding available to the individual,
16 in determining whether the individual is able to comply with
17 post-transplantation medical requirements.

18 (7) SUPPORTED DECISION MAKING. Includes the use of a
19 support person or persons in order to assist an individual in
20 making medical decisions, communicate information to the
21 individual, or ascertain an individual's wishes, including all
22 of the following:

- 23 a. Inclusion of the individual's attorney-in-fact,
24 health care proxy, or any person of the individual's choice in
25 communications about the individual's medical care.

- 26 b. Permitting the individual to select a person of
27 his or her choice for the purposes of supporting that

1 individual in communicating, processing information, or making
2 medical decisions.

3 c. Provision of auxiliary aids and services to
4 facilitate the individual's ability to communicate and process
5 health-related information, including use of assistive
6 communication technology.

7 d. Provision of information to persons designated by
8 the individual consistent with the federal Health Insurance
9 Portability and Accountability Act of 1996, and other
10 applicable laws, rules, and regulations governing disclosure
11 of health information.

12 e. Provision of health information in a format that
13 is readily understandable by the individual.

14 f. If the individual has a court-appointed guardian
15 or other individual responsible for making medical decisions
16 on behalf of the individual, any measures to ensure that the
17 individual is included in decisions involving his or her own
18 health care and that medical decisions are in accordance with
19 the individual's own expressed interest.

20 Section 4. (a) A covered entity may not do any of
21 the following based solely on a qualified individual's
22 disability:

23 (1) Consider an individual ineligible to receive an
24 anatomical gift or organ transplant.

25 (2) Deny medical and other services related to
26 transplantation, including evaluation, surgery, counseling,
27 and post-transplantation treatment and services.

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

5 (4) Refuse to place an individual on an organ
6 transplant waiting list.

7 (5) Place the individual at a lower priority
8 position on the list than the position at which he or she
9 would have been placed if not for his or her disability.

10 (6) Decline insurance coverage for any procedure
11 associated with the receipt of the anatomical gift or organ
12 transplant, including post-transplantation care.

13 (b) (1) Notwithstanding subsection (a), a covered
14 entity may take a qualified individual's disability into
15 account when making treatment or coverage recommendations or
16 decisions, solely to the extent that the disability has been
17 found by a physician, following an individualized evaluation
18 of the individual, to be medically significant to the
19 provision of the anatomical gift or organ transplant.

20 (2) If a qualified individual has the necessary
21 support system to assist the individual in complying with
22 post-transplantation medical requirements, a covered entity
23 may not consider the individual's inability to independently
24 comply with the post-transplantation medical requirements to
25 be medically significant for the purposes of subdivision (1).

26 (c) A covered entity shall make reasonable
27 modifications in policies, practices, or procedures, when the

1 modifications are necessary to allow a qualified individual
2 access to services, including transplantation-related
3 counseling, information, coverage, or treatment, unless the
4 covered entity can demonstrate that making the modifications
5 would fundamentally alter the nature of the services.

6 (d) A covered entity shall implement measures as
7 necessary to ensure that a qualified individual is not denied
8 services, including transplantation-related counseling,
9 information, coverage, or treatment, due to the absence of
10 auxiliary aids and services, unless the covered entity can
11 demonstrate that implementation of the measures would
12 fundamentally alter the nature of the services being offered
13 or would result in an undue burden.

14 Section 5. This act shall become effective on the
15 first day of the third month following its passage and
16 approval by the Governor, or its otherwise becoming law.