

1 HB58  
2 203536-2  
3 By Representative Wood (D)  
4 RFD: Health  
5 First Read: 04-FEB-20  
6 PFD: 01/28/2020

SYNOPSIS: This bill would prohibit discrimination against an individual from receiving an organ transplant based on the individual having a disability.

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

A BILL  
TO BE ENTITLED  
AN ACT

Relating to health care; to prohibit discrimination against an individual with a disability in receiving an anatomical gift or organ transplant based on his or her disability; and to require health care providers and organ 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.