

WEST VIRGINIA LEGISLATURE

2022 REGULAR SESSION

Committee Substitute

for

Senate Bill 647

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[Originating in the Committee on Health and Human
Resources; reported on February 22, 2022]

1 A BILL to amend the Code of West Virginia, 1931, as amended, by adding thereto a new article,
2 designated §16-65-1, §16-65-2, §16-65-3, and §16-65-4, all relating to prohibiting
3 discrimination based on an individual’s mental or physical disability in access to organ
4 transplantation; and providing enforcement mechanisms.

Be it enacted by the Legislature of West Virginia:

ARTICLE 65. NONDISCRIMINATION IN ACCESS TO ORGAN TRANSPLANTATION.

§16-65-1. Legislative intent.

1 The Legislature finds that:

2 (1) A mental or physical disability does not diminish a person’s right to health care;

3 (2) The “Americans with Disabilities Act of 1990” prohibits discrimination against persons
4 with disabilities, yet many individuals with disabilities still experience discrimination in accessing
5 critical health care services;

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

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

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

§16-65-2. Definitions.

1 As used in this article:

2 (1) “Disability” has the same meaning set forth in the Americans with Disabilities Act of
3 1990 (ADA), as amended by the ADA Amendments Act of 2008, at 42 U.S.C. § 12102.

4 (2) "Anatomical gift" means a donation of all or part of a human body to take effect after
5 the donor's death for the purpose of transplantation or transfusion.

6 (3) "Auxiliary aids and services" mean an aid or service that is used to provide information
7 to a person with cognitive, intellectual, neurological, or physical disability and is available in a
8 format or manner that allows the person to better understand the information and may include:

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

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

13 (C) Provision of information in a format that is accessible for individuals with cognitive,
14 neurological, developmental, and/or intellectual disabilities;

15 (D) Provision of supported decision-making services;

16 (E) Acquisition or modification of equipment or devices; and

17 (F) Other similar services and actions.

18 (4) "Covered entity" means:

19 (A) Any licensed provider of health care services, including licensed health care
20 practitioners, hospitals, nursing facilities, laboratories, intermediate care facilities, psychiatric
21 residential treatment facilities, institutions for individuals with intellectual or developmental
22 disabilities, and prison health centers; or

23 (B) Any entity responsible for matching anatomical gift donors to potential recipients.

24 (5) "Organ transplant" means the transplantation or transfusion of a part of a human body
25 into the body of another for the purpose of treating or curing a medical condition.

26 (6) "Qualified individual" means an individual who has a disability and meets the essential
27 eligibility requirements for the receipt of an anatomical gift with or without any of the following:

28 (A) Individuals or entities available to support and assist the person with an anatomical
29 gift or transplantation;

30 (B) Auxiliary aids or services; or

31 (C) Reasonable modifications to the policies or practices of a covered entity.

32 (7) "Reasonable modifications to policies or practices" may include:

33 (A) Communication with individuals responsible for supporting an individual with post-
34 surgical and post-transplantation care, including medication; or

35 (B) Consideration of support networks available to the individual, including family, friends,
36 and home and community-based services, including home and community-based services funded
37 through Medicaid, Medicare, another health plan in which the individual is enrolled, or any
38 program or source of funding available to the individual, in determining whether the individual is
39 able to comply with post-transplant medical requirements;

40 (8) "Supported decision-making" includes use of a support person or persons in order to
41 assist an individual in making medical decisions, communicate information to the individual, or
42 ascertain an individual's wishes, including:

43 (A) Inclusion of the individual's attorney-in-fact, health care proxy, or any person of the
44 individual's choice in communications about the individual's medical care;

45 (B) Permitting the individual to select a person of their choice for the purposes of
46 supporting that individual in communicating, processing information, or making medical decisions;

47 (C) Provision of auxiliary aids and services to facilitate the individual's ability to
48 communicate and process health-related information, including use of assistive communication
49 technology;

50 (D) Provision of information to persons designated by the individual, consistent with the
51 provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), 42 U.S.C.
52 § 1301 et seq., and other applicable laws and regulations governing disclosure of health
53 information;

54 (E) Provision of health information in a format that is readily understandable by the
55 individual; or

56 (F) If the individual has a court-appointed guardian or other individual responsible for
57 making medical decisions on behalf of the individual, any measures to ensure that the individual
58 is included in decisions involving his or her own health care and that medical decisions are in
59 accordance with the individual's own expressed interests.

§16-65-3. Discrimination prohibited.

1 (a) A covered entity may not, solely on the basis of a qualified individual's mental or
2 physical disability:

3 (1) Deem a qualified individual ineligible to receive an anatomical gift or organ transplant;

4 (2) Deny a qualified individual medical and related services related to organ
5 transplantation, including evaluation, surgery, counseling, post-operative treatment and services;

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

8 (4) Refuse to place a qualified individual on an organ transplant waiting list, or placement
9 of the individual at a lower-priority position on the list than the position at which he or she would
10 have been placed if not for his or her disability; or

11 (5) Decline insurance coverage to a qualified individual for any procedure associated with
12 the receipt of the anatomical gift, including post-transplantation care;

13 (b) Notwithstanding subsection (a) of this section, a covered entity may take an individual's
14 disability into account when making treatment or coverage recommendations or decisions, solely
15 to the extent that the physical or mental disability has been found by a physician or surgeon,
16 following an individualized evaluation of the potential recipient, to be medically significant to the
17 provision of the anatomical gift. The provisions of this section shall not be deemed to require
18 referrals or recommendations for, or the performance of, medically inappropriate organ
19 transplants.

20 (c) If an individual has the necessary support system to assist the individual in complying
21 with post-transplant medical requirements, an individual's inability to independently comply with

22 those requirements shall not be deemed to be medically significant for the purposes of subsection
23 (b) of this section.

24 (d) A covered entity shall make reasonable modifications in policies, practices, or
25 procedures, when such modifications are necessary to make services such as transplantation-
26 related counseling, information, coverage, or treatment available to qualified individuals with
27 disabilities, unless the entity can demonstrate that making such modifications would
28 fundamentally alter the nature of such services;

29 (e) A covered entity shall take steps necessary to ensure that no qualified individual with
30 a disability is denied services such as transplantation-related counseling, information, coverage,
31 or treatment because of the absence of auxiliary aids and services, unless the entity can
32 demonstrate that taking those steps would fundamentally alter the nature of the services being
33 offered or would result in an undue burden;

34 (f) A covered entity shall otherwise comply with the requirements of Titles II and III of the
35 Americans with Disabilities Act of 1990, as amended by the Americans with Disabilities Act
36 Amendments Act of 2008.

37 (g) The provisions of this section apply to each part of the organ transplant process.

§16-65-4. Enforcement.

1 (a) The remedy for violations of this article are the same as those available under Titles II
2 and III of the Americans with Disabilities Act, 42 U.S.C. §§ 12131-12189.

3 (b) The court shall accord priority on its calendar and expeditiously proceed with an action
4 brought to seek any remedy authorized by law for purposes of enforcing compliance with the
5 provisions of this article.