SPONSOR: Rep. Heffernan & Rep. M. Smith & Sen. McDowell & Sen. Poore
Reps. Baumbach, Bentz, Hensley, Hudson, Kowalko, Mitchell, D. Short, Viola, Wilson

HOUSE OF REPRESENTATIVES
149th GENERAL ASSEMBLY

# HOUSE BILL NO. 21
AND
HOUSE AMENDMENT NO. 2

AN ACT TO AMEND TITLE 16 OF THE DELAWARE CODE RELATING TO NONDISCRIMINATION IN ACCESS TO ORGAN TRANSPLANTATION.

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

Section 1. Add a new Subchapter to Chapter 27, Title 16 of the Delaware Code by making deletions as shown by strikethrough and insertions as shown by underline as follows:

Subchapter III. Nondiscrimination in Access to Organ Transplantation.

§ 2741. Legislative Intent.

The General Assembly finds that:

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

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

(3) Individuals with mental and physical disabilities are at risk of being denied life-saving 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 such compliance;

(4) Although organ transplant centers must consider medical and psychosocial criteria when determining if a patient is suitable 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 non- discriminatory distribution of organs; and

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

§ 2742. Definitions.

For purposes of this subchapter:



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Draft: 06/08/2017 08:47 AM

(1) "Disability" shall have the same meaning set forth in the Americans with Disabilities Act Americans with Disabilities Act of 1990 (ADA), as amended by the ADA Amendments Act of 2008, at 42 U.S.C. § 12102.

(2) "Auxiliary aids and services" includes any or all of the following:

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

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

c. Provision of information in a format that is accessible for individuals with cognitive, neurological, developmental, and/or intellectual disabilities.

d. Provision of supported decision-making services.

e. Acquisition or modification of equipment or devices.

f. Services and actions similar to those described in paragraphs (2)a. through (2)e. of this section.

(3) "Qualified individual" means an individual who, with or without the support networks available to them, provision of auxiliary aids and services, and/or reasonable modifications to policies or practices, meets the essential eligibility requirements for the receipt of an anatomical gift.

(4) The phrase "reasonable modifications to policies or practices" includes:

a. Communication with individuals responsible for supporting an individual with post-surgical and post-transplantation care, including medication.

b. Consideration of support networks available to the individual, including family, friends, and home and community-based services, including home and community-based services funded through Medicaid, Medicare, another health plan in which the individual is enrolled, or any program or source of funding available to the individual, in determining whether the individual is able to comply with post-transplant medical requirements.

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

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

(7) The term "supported decisionmaking" includes use of a support person to assist an individual in making medical decisions, communicate information to the individual, or ascertain an individual's wishes, including:

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

b. Permitting the individual access to a person of their choice for the purposes of supporting that individual in communicating, processing information, or making medical decisions;

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

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

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

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

(8) "Covered entity" means:

a. Any licensed provider of health care services, including licensed health care practitioners, hospitals, nursing facilities, laboratories, intermediate care facilities, psychiatric residential treatment facilities, institutions for individuals with intellectual or developmental disabilities, and prison health centers; or

b. Any entity responsible for matching anatomical gift donors to potential recipients.

§ 2743. Discrimination prohibited.

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

a. Deem an individual ineligible to receive an anatomical gift or organ transplant;

b. Deny medical and related services related to organ transplantation, including evaluation, surgery, counseling, post-operative treatment and services;

c. Refuse to refer the individual to a transplant center or other related specialist for the purpose of evaluation or receipt of an organ transplant;

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

e. Decline insurance coverage for any procedure associated with the receipt of the anatomical gift, including post-transplantation care;

(b) Notwithstanding subsection (a) of this section, a covered entity may take an individual's disability into account when making treatment and/or coverage recommendations or decisions, solely to the extent that the physical or mental

disability has been found by a physician or surgeon, following an individualized evaluation of the potential recipient, to be medically significant to the provision of the organ transplant. The provisions of this section shall not be deemed to require referrals or recommendations for, or the performance of, medically inappropriate organ transplants.

(c) If an individual has the necessary support system to assist the individual in complying with post-transplant medical requirements, an individual's inability to independently comply with those requirements shall not be deemed to be medically significant for the purposes of subsection (b) of this section.

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

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

(f) A covered entity shall otherwise comply with the requirements of Titles II and III of the Americans with Disabilities Act and ADA Amendments Act of 2008.

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

§ 2744. Remedies.

(a) Any person subjected to discrimination in violation of this subchapter or who has reasonable grounds for believing that such person is about to be subjected to discrimination in violation of this subchapter may bring an action in the Court of Chancery for injunctive or other equitable relief.

(b) The court shall accord priority on its calendar and expeditiously proceed with an action brought under this section.

(c) Nothing in this section is intended to limit or replace available remedies under the ADA or any other applicable law.