STATE OF NEW YORK

455

2019-2020 Regular Sessions

IN SENATE

(Prefiled)

January 9, 2019

Introduced by Sen. ORTT -- read twice and ordered printed, and when printed to be committed to the Committee on Mental Health and Developmental Disabilities

AN ACT to amend the mental hygiene law, in relation to fairness in organ donations to persons with physical or mental disabilities

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

Section 1. The mental hygiene law is amended by adding a new article 35 to read as follows:

ARTICLE 35

ORGAN DONATION FAIRNESS ACT

Section 35.01 Legislative intent.

35.03 Definitions.

35.05 Discrimination prohibited.

35.07 Enforcement.

§ 35.01 Legislative intent.

The legislature finds that:

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

(b) The Americans with Disabilities Act of 1990, 42 USC 12101, prohibits discrimination against persons with disabilities, yet many individuals with disabilities still experience discrimination in accessing critical health care services;

(c) Individuals with mental and physical disabilities have historically been 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;

(d) Although organ transplant centers must consider medical and psychosocial criteria when determining if a patient is suitable to

EXPLANATION--Matter in *italics* (underscored) is new; matter in brackets [-] is old law to be omitted.

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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

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

§ 35.03 Definitions.

As used in this article:

(a) the term "disability" shall have the same meaning set forth in the Americans with Disabilities Act of 1990 as amended by the ADA Amendments Act of 2008, at 42 USC 12102.

(b) the term "auxiliary aids and services" shall include:

1. qualified interpreters or other effective methods of making aurally delivered materials available to individuals with hearing impairments;

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

3. provision of information in a format that is accessible for individuals with cognitive, neurological, developmental, or intellectual disabilities;

4. provision of supported decision making services;

5. acquisition or modification of equipment or devices; and

6. other similar services and actions.

(c) the term "qualified individual" shall mean an individual who, with or without the support networks available to them, provision of auxiliary aids and services, or reasonable modifications to policies or practices, meets the essential eligibility requirements for the receipt of an anatomical gift.

(d) the term "reasonable modifications to policies or practices" shall include:

1. communication with individuals responsible for supporting an individual with post-surgical and post-transplantation care, including medication; and

2. 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.

(e) the term "anatomical gift" shall mean 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.

(f) the term "organ transplant" shall mean 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.

(g) the term "supported decision making" shall include the use of a support person or persons in order to assist an individual in making medical decisions, communicate information to the individual, or ascertain an individual's wishes, including:

1. 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;

2. permitting the individual to designate a person of their choice for the purposes of supporting that individual in communicating, processing information, or making medical decisions;

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

4. provision of information to persons designated by the individual, consistent with the provisions of the Health Insurance Portability and Accountability Act of 1996, 42 USC 1301, and other applicable laws and regulations governing disclosure of health information;

5. provision of health information in a format that is readily understandable by the individual; and

6. 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.

(h) the term "covered entity" shall mean:

1. 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

2. any entity responsible for matching anatomical gift donors to potential recipients.

§ 35.05 Discrimination prohibited.

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

1. deem an individual ineligible to receive an anatomical gift or organ transplant;

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

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

4. 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

5. decline insurance coverage for any procedure associated with the receipt of the anatomical gift, including post-transplantation care.

(b) Notwithstanding subdivision (a) of this section, a covered entity may take an individual's disability into account when making treatment 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 anatomical gift. 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 subdivision (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, 42 USC 12131, and ADA Amendments Act of 2008.

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

§ 35.07 Enforcement.

(a) The remedy for violations of this article shall be the same as those available under Titles II and III of the Americans with Disabilities Act, 42 USC 12131.

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

§ 2. This act shall take effect immediately.