## LEGISLATURE OF NEBRASKA ONE HUNDRED SIXTH LEGISLATURE SECOND SESSION

## **LEGISLATIVE BILL 994**

Introduced by Murman, 38; Cavanaugh, 6.

Read first time January 14, 2020

Committee: Judiciary

- 1 A BILL FOR AN ACT relating to health; to adopt the Organ Transplant
- 2 Fairness Act.
- 3 Be it enacted by the people of the State of Nebraska,

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1 Section 1. Sections 1 to 5 of this act shall be known and may be

- 2 cited as the Organ Transplant Fairness Act.
- 3 Sec. 2. <u>The Legislature finds that:</u>
- 4 (1) A mental or physical disability does not diminish a person's
- 5 <u>right to health care;</u>
- 6 (2) State and federal law prohibit discrimination against persons
- 7 with disabilities, yet many individuals with disabilities still
- 8 experience discrimination in accessing critical health care services;
- 9 (3) Individuals with mental and physical disabilities have
- 10 historically been denied life-saving organ transplants based on
- 11 <u>assumptions that their lives are less worthy, that they are incapable of</u>
- 12 <u>complying with post-transplant medical regimens, or that they lack</u>
- 13 <u>adequate support systems to ensure such compliance;</u>
- 14 (4) Although organ transplant centers must consider medical and
- 15 psychosocial criteria when determining if a patient is suitable to
- 16 <u>receive an organ transplant, transplant centers that participate in</u>
- 17 medicare, medicaid, and other federally funded programs are required to
- 18 use patient selection criteria that result in a fair and
- 19 <u>nondiscriminatory distribution of organs; and</u>
- 20 (5) Nebraska residents in need of organ transplants are entitled to
- 21 <u>assurances that they will not encounter discrimination on the basis of a</u>
- 22 <u>disability</u>.
- Sec. 3. <u>For purposes of the Organ Transplant Fairness Act:</u>
- 24 (1) Auxiliary aids and services includes:
- 25 (a) Qualified interpreters or other effective methods of making
- 26 aurally delivered materials available to deaf or hard of hearing
- 27 <u>individuals;</u>
- 28 <u>(b) Qualified readers, taped texts, or other effective methods of</u>
- 29 making visually delivered materials available to individuals with visual
- 30 <u>impairments;</u>
- 31 (c) Provision of information in a format that is accessible for

1 individuals with cognitive, neurological, developmental, or intellectual

- 2 disabilities;
- 3 (d) Provision of aids and services to facilitate the individual's
- 4 ability to communicate and process health-related information;
- 5 (e) The use of assistive communication technology;
- 6 (f) Provision of supported decisionmaking services;
- 7 (g) Acquisition or modification of equipment or devices; and
- 8 (h) Other similar services and actions;
- 9 (2)(a) Covered entity means:
- 10 (i) A licensed provider of health care services, including, but not
- 11 limited to, a licensed health care practitioner, a hospital, a nursing
- 12 <u>facility</u>, a laboratory, an <u>intermediate care facility</u>, a <u>psychiatric</u>
- 13 residential treatment facility, an institution for individuals with
- 14 intellectual or developmental disabilities, or a prison health center; or
- 15 (ii) An entity responsible for matching organ transplants to
- 16 potential recipients.
- 17 (b) Covered entity includes any private or public entity, including
- 18 the state, a governmental agency created by the state, or a political
- 19 <u>subdivision</u>;
- 20 (3) Disability has the same meaning as in 42 U.S.C. 12102, as such
- 21 <u>section existed on January 1, 2020;</u>
- 22 (4) Organ transplant means the transplantation or transfusion of a
- 23 part of a human body into the body of another for the purpose of treating
- 24 or curing a medical condition;
- 25 (5) Qualified individual means an individual who has a disability
- 26 and meets the essential eligibility requirements for the receipt of an
- 27 <u>organ transplant, with or without auxiliary aids and services or</u>
- 28 reasonable modifications to policies or practices of a covered entity;
- 29 <u>(6) Reasonable modifications to policies or practices may include</u>
- 30 the following, in determining whether an individual is able to comply
- 31 with post-transplant medical requirements:

- 1 (a) Communication with persons responsible for supporting the
- 2 individual with post-surgical and post-transplantation care, including
- 3 medication; and
- 4 (b) Consideration of support networks available to the individual,
- 5 including family, friends, and home and community-based services,
- 6 including home and community-based services funded through medicaid,
- 7 medicare, another health plan in which the individual is enrolled, or any
- 8 program or source of funding available to the individual; and
- 9 (7) Supported decisionmaking services includes, but is not limited
- 10 to:
- 11 <u>(a) The use of a support person or persons in order to assist the</u>
- 12 <u>individual in making medical decisions, communicate information to the</u>
- 13 <u>individual</u>, or ascertain an individual's wishes;
- 14 (b) Inclusion of the individual's power of attorney, power of
- 15 attorney for health care, or any person of the individual's choice in
- 16 communications about the individual's medical care;
- 17 (c) Permitting the individual to designate a person of their choice
- 18 for the purposes of supporting that individual in communicating,
- 19 processing information, or making medical decisions;
- 20 <u>(d) Provision of information to persons designated by the</u>
- 21 individual, consistent with the provisions of the Health Insurance
- 22 Portability and Accountability Act of 1996, 42 U.S.C. 1301 et seq., and
- 23 any other applicable laws and regulations governing disclosure of health
- 24 <u>information;</u>
- 25 (e) Provision of health information in a format that is readily
- 26 understandable by the individual; and
- 27 (f) If the individual has a court-appointed guardian or other person
- 28 responsible for making medical decisions on behalf of the individual, any
- 29 measures to ensure that the individual is included in decisions involving
- 30 the individual's own health care and that medical decisions are in
- 31 accordance with the individual's own expressed interests.

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- 1 Sec. 4. (1) Except as provided in subsection (2) of this section, a
- 2 covered entity shall not, solely on the basis of a qualified individual's
- 3 <u>mental or physical disability:</u>
- 4 (a) Deem the individual ineligible to receive an organ transplant;
- 5 (b) Deny services related to organ transplantation, including, but
- 6 <u>not limited to, evaluation, surgery, counseling, and post-operative</u>
- 7 treatment and services;
- 8 <u>(c) Refuse to refer the individual to a transplant center or other</u>
- 9 related specialist for the purpose of evaluation or receipt of an organ
- 10 transplant;
- 11 (d) Refuse to place the individual on an organ transplant waiting
- 12 list;
- 13 <u>(e) Place an individual at a lower-priority position on an organ</u>
- 14 transplant waiting list than the position at which the individual would
- 15 <u>have been placed if not for the individual's disability; or</u>
- (f) Decline insurance coverage for any procedure associated with the
- 17 receipt of an organ transplant, including post-transplantation care.
- 18 (2) A covered entity may take an individual's disability into
- 19 account when making treatment or coverage recommendations or decisions,
- 20 solely to the extent that the physical or mental disability has been
- 21 found by a physician or surgeon, following an individualized evaluation
- 22 of the individual, to be medically significant to the organ transplant.
- 23 <u>(3) This section shall not be construed to require referrals or</u>
- 24 recommendations for, or the performance of, medically inappropriate organ
- 25 <u>transplants</u>.
- 26 (4) If an individual has the necessary support system to assist the
- 27 <u>individual in complying with post-transplant medical requirements, an</u>
- 28 <u>individual's inability to independently comply with those requirements</u>
- 29 <u>shall not be deemed to be medically significant for the purposes of</u>
- 30 subsection (2) of this section.
- 31 (5) A covered entity shall make reasonable modifications to its

- 1 policies, practices, or procedures, when such modifications are necessary
- 2 to make services such as transplantation-related counseling, information,
- 3 coverage, or treatment available to qualified individuals, unless the
- 4 covered entity can demonstrate that making such modifications would
- 5 <u>fundamentally alter the nature of such services.</u>
- 6 (6) A covered entity shall take such steps as may be necessary to
- 7 ensure that no qualified individual is denied services such as
- 8 <u>transplantation-related counseling, information, coverage, or treatment</u>
- 9 because of the absence of auxiliary aids and services, unless the entity
- 10 can demonstrate that taking such steps would fundamentally alter the
- 11 nature of the services being offered or would result in an undue burden.
- 12 <u>(7) A covered entity shall otherwise comply with the requirements of</u>
- 13 <u>Titles II and III of the federal Americans with Disabilities Act of 1990</u>
- 14 and the federal ADA Amendments Act of 2008.
- 15 (8) This section applies to each phase of the organ transplant
- 16 process.
- 17 Sec. 5. (1) A person aggrieved by a violation of the Organ
- 18 Transplant Fairness Act may bring a civil action against a covered
- 19 entity. A successful plaintiff shall be entitled to appropriate relief,
- 20 including temporary or permanent injunctive relief, general and special
- 21 <u>damages, reasonable attorney's fees, and costs.</u>
- 22 (2) The state, governmental agencies created by the state, and
- 23 political subdivisions of the state may be sued upon claims arising under
- 24 the Organ Transplant Fairness Act in the same manner as provided by such
- 25 law for suits against other covered entities.
- 26 (3) All proceedings pursuant to the Organ Transplant Fairness Act
- 27 have the highest priority and shall be advanced on the court docket to
- 28 provide for the earliest practical disposition.