

HOUSE No. 4332

The Commonwealth of Massachusetts

HOUSE OF REPRESENTATIVES, May 25, 2016.

The committee on Public Health to whom was referred the petition (accompanied by bill, House, No. 3271) of James M. Cantwell and others relative to nondiscrimination in access to organ transplants, reports recommending that the accompanying bill (House, No. 4332) ought to pass.

For the committee,

KATE HOGAN.

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**In the One Hundred and Eighty-Ninth General Court
(2015-2016)**

An Act concerning nondiscrimination in access to organ transplantation.

Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:

1 SECTION 1. Chapter 111 of the General Laws, as appearing in the 2014 Official
2 Edition, is hereby amended by adding after section 235 the following section:-

3 Section 236. (a) As used in this section, the following terms shall have the following
4 meanings:

5 “Auxiliary aids and services”, as defined in the Americans with Disabilities Act of 1990,
6 as amended by the ADA Amendments Act of 2008, at 42 U.S.C. § 12102.

7 “Covered entity”, any licensed provider of health care services, including licensed health
8 care practitioners, hospitals, nursing facilities, laboratories, intermediate care facilities,
9 psychiatric residential treatment facilities, institutions for individuals with intellectual or
10 developmental disabilities, and prison health centers; or any entity responsible for matching
11 anatomical gift donors to potential recipients.

12 “Disability”, as defined in the Americans with Disabilities Act of 1990, as amended by
13 the ADA Amendments Act of 2008, at 42 U.S.C. § 12102.

14 “Organ transplant”, the transplantation or transfusion of a part of a human body into the
15 body of another for the purpose of treating or curing a medical condition.

16 “Qualified individual”, an individual who, with or without the support networks available
17 to them, provision of auxiliary aids and services, or reasonable modifications to policies or
18 practices, meets the essential eligibility requirements for the receipt of an anatomical gift.

19 “Reasonable modification” or “reasonable modifications to policies or practices”, may
20 include, but not be limited to: (i) communication with individuals responsible for supporting an
21 individual with post-surgical and post-transplantation care, including medication; (ii)
22 consideration of support networks available to the individual, including family, friends, and
23 home and community-based services, including home and community-based services funded
24 through Medicaid, Medicare, another health plan in which the individual is enrolled, or any
25 program or source of funding available to the individual, in determining whether the individual is
26 able to comply with post-transplant medical requirements.

27 “Supported decision making”, the use of a support person to assist an individual in
28 making medical decisions, communicate information to the individual, or ascertain an
29 individual’s wishes, including: (i) inclusion of the individual’s attorney-in-fact, health care
30 proxy, or any person of the individual’s choice in communications about the individual’s medical
31 care; (ii) permitting the individual to a person of their choice for the purposes of supporting that
32 individual in communicating, processing information, or making medical decisions; (iii)
33 provision of auxiliary aids and services to facilitate the individual’s ability to communicate and

34 process health-related information, including use of assistive communication technology; (iv)
35 provision of information to persons designated by the individual, consistent with the provisions
36 of the Health Insurance Portability and Accountability Act of 1996, 42 U.S.C. § 1301 et seq., and
37 other applicable laws and regulations governing disclosure of health information; (v) provision
38 of health information in a format that is readily understandable by the individual; and (vi) the
39 individual has a court-appointed guardian or other individual responsible for making medical
40 decisions on behalf of the individual, any measures to ensure that the individual is included in
41 decisions involving his or her own health care and that medical decisions are in accordance with
42 the individual's own expressed interests.

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

45 (1) deem an individual ineligible to receive an anatomical gift or organ transplant;

46 (2) deny medical and related services related to organ transplantation, including
47 evaluation, surgery, counseling, post-operative treatment and services;

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

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

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

55 (c) Notwithstanding the provisions of subsection (b), a covered entity may take an
56 individual's disability into account when making treatment or coverage recommendations or
57 decisions, solely to the extent that the physical or mental disability has been found by a physician
58 or surgeon, following an individualized evaluation of the potential recipient, to be medically
59 significant to the provision of the anatomical gift.

60 This section shall not be deemed to require referrals or recommendations for, or the
61 performance of, medically inappropriate organ transplants.

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

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

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

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

78 (h) This section shall apply to each part of the organ transplant process.

79 (i) Any person subjected to discrimination in violation of section 7 or who has reasonable
80 grounds for believing that such person is about to be subjected to discrimination in violation of
81 section 7 may bring an action in the appropriate court for injunctive or other equitable relief.

82 The attorney general shall investigate alleged violations of this section, and shall
83 undertake periodic reviews of compliance of covered entities.

84 If the attorney general has reasonable cause to believe that (i) any person or group of
85 persons is engaged in a pattern or practice of discrimination under this section; or (ii) any person
86 or group of persons has been discriminated against under this section and such discrimination
87 raises an issue of general public importance, the attorney general may commence a civil action in
88 any appropriate state court.

89 In a civil action commenced under this subsection, the court may:

90 (i) grant any equitable relief that such court considers to be appropriate, including, to
91 the extent required by this section;

92 (ii) grant injunctive, temporary, preliminary, or permanent relief;

93 (iii) require an auxiliary aid or service, modification of policy, practice, or procedure,
94 or alternative method;

95 (iv) require that facilities be made readily accessible to and usable by individuals with
96 disabilities;

97 (v) award such other relief as the court considers to be appropriate, including
98 monetary damages to persons aggrieved.

99 In addition, the court may assess a civil penalty against the entity in an amount not to
100 exceed \$50,000 for a first violation; and an amount not to exceed \$100,000 for any subsequent
101 violation. For purposes of determining under this paragraph whether a first or subsequent
102 violation has occurred, a determination in a single action, by judgment or settlement, that the
103 covered entity has engaged in more than one discriminatory act shall be counted as a single
104 violation.

105 (j) The department may adopt regulations to implement the provisions of this section.