

117TH CONGRESS
1ST SESSION

S. _____

To prohibit discrimination on the basis of mental or physical disability in cases of organ transplants.

IN THE SENATE OF THE UNITED STATES

Mr. RUBIO (for himself and Ms. HASSAN) introduced the following bill; which was read twice and referred to the Committee on _____

A BILL

To prohibit discrimination on the basis of mental or physical disability in cases of organ transplants.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Charlotte Woodward
5 Organ Transplant Discrimination Prevention Act”.

6 **SEC. 2. FINDINGS.**

7 Congress finds the following:

8 (1) The Americans with Disabilities Act of
9 1990, section 504 of the Rehabilitation Act of 1973,
10 and section 1557 of the Patient Protection and Af-

1 affordable Care Act prohibit discrimination against in-
2 dividuals with disabilities in organ transplantation
3 and the allocation of organs.

4 (2) Despite those prohibitions, there are find-
5 ings and cases that show, as is documented by the
6 National Council on Disability and others, that indi-
7 viduals with disabilities are being denied organ
8 transplants and related services based solely on the
9 fact that those individuals have a disability.

10 (3) More than 25 States have crafted State-
11 level policy to prohibit organ transplant discrimina-
12 tion against individuals with disabilities. Federal ac-
13 tion, however, is required to protect individuals with
14 disabilities and to enforce existing law regardless of
15 the State in which they live.

16 (4) The current situation, with continuing cases
17 of discrimination against individuals with disabili-
18 ties, calls for further clarity by Congress about
19 which actions constitute discrimination under cur-
20 rent law, which entities are covered, and the rem-
21 edies available to individuals experiencing potential
22 discrimination.

23 (5) Licensed providers of health care services
24 that provide organ transplants and related services
25 in exchange for medical fees are engaging in an eco-

1 nomic transaction with patients that occurs in or
2 substantially impacts interstate commerce.

3 (6) There are 11 geographic regions that are
4 used in the national administration of organ alloca-
5 tion in the United States, with organs being trans-
6 ported across State lines for transplantation proce-
7 dures.

8 (7) Discrimination in organ transplantation
9 limits individuals with disabilities from participating
10 in health care transactions in a manner that allows
11 equal access to interstate commerce.

12 (8) The existence of discrimination against indi-
13 viduals with disabilities in the provision of organ
14 transplantation and related services burdens the flow
15 of organs through legal channels of interstate com-
16 merce.

17 **SEC. 3. DEFINITIONS.**

18 In this Act:

19 (1) AUXILIARY AIDS AND SERVICES.—The term
20 “auxiliary aids and services” includes—

21 (A) qualified interpreters or other effective
22 methods of making aurally delivered materials
23 available to individuals with a hearing impair-
24 ment;

1 (B) qualified readers, taped texts, or other
2 effective methods of making visually delivered
3 materials available to individuals with a visual
4 impairment;

5 (C) information in a format that is acces-
6 sible for individuals with a cognitive, neuro-
7 logical, developmental, or intellectual disability;

8 (D) supported decisionmaking services;
9 and

10 (E) acquisition or modification of equip-
11 ment or devices.

12 (2) COVERED ENTITY.—The term “covered en-
13 tity” means—

14 (A) any licensed provider of health care
15 services, including licensed health care practi-
16 tioners, hospitals, nursing facilities, labora-
17 tories, intermediate care facilities, psychiatric
18 residential treatment facilities, institutions for
19 individuals with intellectual or developmental
20 disabilities, and prison health centers, that—

21 (i) is in interstate commerce; or

22 (ii) provides health care services in a
23 manner that—

1 (I) substantially affects or has a
2 substantial relation to interstate com-
3 merce; or

4 (II) includes use of an instru-
5 ment (including an instrument of
6 transportation or communication) of
7 interstate commerce; or

8 (B) any transplant center or entity respon-
9 sible for matching human organ donors to po-
10 tential recipients that is in interstate commerce,
11 or that provides the matching services in a
12 manner described in subparagraph (A)(ii).

13 (3) DISABILITY.—The term “disability” has the
14 meaning given the term in section 3 of the Ameri-
15 cans with Disabilities Act of 1990 (42 U.S.C.
16 12102).

17 (4) HUMAN ORGAN.—The term “human organ”
18 has the meaning given the term in section 301(c) of
19 the National Organ Transplant Act (42 U.S.C.
20 274e(c)).

21 (5) ORGAN TRANSPLANT.—The term “organ
22 transplant” means the transplantation or trans-
23 fusion of a donated human organ into the body of
24 another human for the purpose of treating or curing
25 a medical condition.

1 (6) QUALIFIED INDIVIDUAL.—The term “quali-
2 fied individual” means an individual who, with or
3 without a support network, provision of auxiliary
4 aids and services, or reasonable modifications to
5 policies or practices, meets eligibility requirements
6 for the receipt of a human organ.

7 (7) REASONABLE MODIFICATIONS TO POLICIES
8 OR PRACTICES.—The term “reasonable modifications
9 to policies or practices” includes—

10 (A) communication with individuals re-
11 sponsible for supporting an individual with
12 postsurgical or other care following an organ
13 transplant or related services, including support
14 with medication; and

15 (B) consideration, in determining whether
16 an individual will be able to comply with health
17 requirements following an organ transplant or
18 receipt of related services, of support networks
19 available to the individual, including family,
20 friends, and providers of home and community-
21 based services, including home and community-
22 based services funded through the Medicare or
23 Medicaid program under title XVIII or XIX, re-
24 spectively, of the Social Security Act (42 U.S.C.
25 1395 et seq., 1396 et seq.), another health plan

1 in which the individual is enrolled, or any pro-
2 gram or source of funding available to the indi-
3 vidual.

4 (8) RELATED SERVICES.—The term “related
5 services” means services related to an organ trans-
6 plant that consist of—

7 (A) evaluation;

8 (B) counseling;

9 (C) treatment, including postoperative
10 treatment, and care;

11 (D) provision of information; and

12 (E) any other service recommended or re-
13 quired by a physician.

14 (9) SECRETARY.—The term “Secretary” means
15 the Secretary of Health and Human Services.

16 (10) SUPPORTED DECISIONMAKING.—The term
17 “supported decisionmaking” means the use of a sup-
18 port person to assist an individual in making health
19 care decisions, communicate information to the indi-
20 vidual, or ascertain an individual’s wishes. Such
21 term includes—

22 (A) the inclusion of the individual’s attor-
23 ney-in-fact or health care proxy, or any person
24 of the individual’s choice, in communications
25 about the individual’s health care;

1 (B) permitting the individual to designate
2 a person of the individual's choice for the pur-
3 poses of supporting that individual in commu-
4 nicating, processing information, or making
5 health care decisions;

6 (C) providing auxiliary aids and services
7 described in subparagraph (A), (B), (C), or (E)
8 of paragraph (1) to facilitate the individual's
9 ability to communicate and process health-re-
10 lated information, including providing use of as-
11 sistive communication technology;

12 (D) providing health information to per-
13 sons designated by the individual, consistent
14 with the regulations promulgated under section
15 264(c) of the Health Insurance Portability and
16 Accountability Act of 1996 (42 U.S.C. 1320d-
17 2 note) and other applicable laws and regula-
18 tions governing disclosure of health informa-
19 tion;

20 (E) providing health information in a for-
21 mat that is readily understandable by the indi-
22 vidual; and

23 (F) working with a court-appointed guard-
24 ian or other individual responsible for making
25 health care decisions on behalf of the individual,

1 to ensure that the individual is included in deci-
2 sions involving the health care of the individual
3 and that health care decisions are in accordance
4 with the individual's own expressed interests.

5 (11) SUPPORT NETWORK.—The term “support
6 network” means, with respect to a person, one or
7 more individuals who are—

8 (A) selected by the person or by the person
9 and the guardian of the person, to provide as-
10 sistance to that person or guidance to that per-
11 son in understanding issues, making plans for
12 the future, or making complex decisions; and

13 (B) who may include the family members,
14 friends, unpaid supporters, members of the reli-
15 gious congregation, and appropriate personnel
16 at a community center, of or serving the per-
17 son.

18 **SEC. 4. PROHIBITION OF DISCRIMINATION.**

19 (a) IN GENERAL.—Subject to subsection (b), a cov-
20 ered entity may not, solely on the basis of a qualified indi-
21 vidual's mental or physical disability—

22 (1) determine that the individual is ineligible to
23 receive an organ transplant or related services;

24 (2) deny the individual an organ transplant or
25 related services;

1 (3) refuse to refer the individual to an organ
2 transplant center or other related specialist for the
3 purpose of receipt of an organ transplant or other
4 related services;

5 (4) refuse to place the individual on an organ
6 transplant waiting list, or place the individual at a
7 lower-priority position on the list than the position
8 at which the individual would have been placed if not
9 for the disability of the individual; or

10 (5) decline insurance coverage for the individual
11 for any procedure associated with the receipt of an
12 organ transplant or for related services, which proce-
13 dure or services, respectively, would be covered
14 under such insurance for such individual if not for
15 the disability of the individual.

16 (b) EXCEPTION.—

17 (1) IN GENERAL.—

18 (A) MEDICALLY SIGNIFICANT DISABIL-
19 ITIES.—Notwithstanding subsection (a), a cov-
20 ered entity may take a qualified individual's
21 physical or mental disability into account when
22 making a health care treatment or coverage rec-
23 ommendation or decision, solely to the extent
24 that the disability has been found by a physi-
25 cian, following an individualized evaluation of

1 the potential recipient, to be medically signifi-
2 cant to the receipt of the organ transplant or
3 related services, as the case may be.

4 (B) CONSTRUCTION.—Subparagraph (A)
5 shall not be construed to require a referral or
6 recommendation for, or the performance of, a
7 medically inappropriate organ transplant or
8 medically inappropriate related services.

9 (2) CLARIFICATION.—If a qualified individual
10 has the necessary support network to provide a rea-
11 sonable assurance that the individual will be able to
12 comply with health requirements following an organ
13 transplant or receipt of related services, as the case
14 may be, the individual's inability to independently
15 comply with those requirements may not be con-
16 strued to be medically significant for purposes of
17 paragraph (1).

18 (c) REASONABLE MODIFICATIONS.—A covered entity
19 shall make reasonable modifications to policies or practices
20 (including procedures) of such entity if such modifications
21 are necessary to make an organ transplant or related serv-
22 ices available to qualified individuals with disabilities, un-
23 less the entity can demonstrate that making such modi-
24 fications would fundamentally alter the nature of such
25 policies or practices.

1 (d) CLARIFICATIONS.—

2 (1) NO DENIAL OF SERVICES BECAUSE OF AB-
3 SENCE OF AUXILIARY AIDS AND SERVICES.—A cov-
4 ered entity shall take such steps as may be nec-
5 essary to ensure that a qualified individual with a
6 disability is not denied a procedure associated with
7 the receipt of an organ transplant or related serv-
8 ices, and insurance coverage for the individual is not
9 declined for a procedure or services described in sec-
10 tion 4(a)(5), because of the absence of auxiliary aids
11 and services, unless the entity can demonstrate that
12 taking such steps would fundamentally alter the na-
13 ture of the procedure or services being offered or
14 would result in an undue burden on the entity.

15 (2) COMPLIANCE WITH OTHER LAW.—Nothing
16 in this Act shall be construed—

17 (A) to prevent a covered entity from pro-
18 viding organ transplants or related services at
19 a level that is greater than the level that is re-
20 quired by this section; or

21 (B) to limit the rights of an individual with
22 a disability under, or to replace or limit the
23 scope of obligations imposed by, the Americans
24 with Disabilities Act of 1990 (42 U.S.C. 12101
25 et seq.) including the provisions added to such

1 Act by the ADA Amendments Act of 2008, sec-
2 tion 504 of the Rehabilitation Act of 1973 (29
3 U.S.C. 794), section 1557 of the Patient Pro-
4 tection and Affordable Care Act (42 U.S.C.
5 18116), or any other applicable law.

6 (3) APPLICATION TO EACH PART OF PROC-
7 ESS.—The provisions of this section apply to each
8 part of the organ transplant process and the process
9 for receipt of related services.

10 **SEC. 5. ENFORCEMENT.**

11 (a) IN GENERAL.—Any individual who alleges that
12 a qualified individual was subject to a violation of section
13 4 by a covered entity—

14 (1) may bring a claim regarding the allegation
15 to the Office for Civil Rights of the Department of
16 Health and Human Services, for expedited resolu-
17 tion; and

18 (2) whether or not such a claim is brought
19 under paragraph (1) or a violation is found pursuant
20 to paragraph (1), may bring a civil action in a dis-
21 trict court of the United States for injunctive or
22 other equitable relief, including the relief described
23 in subsection (b), against such covered entity to ob-
24 tain compliance of such covered entity with such sec-
25 tion.

1 (b) RELIEF AVAILABLE.—The injunctive and equi-
2 table relief available in a civil action brought under sub-
3 section (a)(2), with respect to a covered entity, includes—

4 (1) requiring auxiliary aids and services to be
5 made available by such entity;

6 (2) requiring reasonable modifications to poli-
7 cies or practices (including procedures) of such enti-
8 ty; or

9 (3) requiring that a facility of such entity be
10 made readily accessible and usable.

11 (c) EXPEDITED REVIEW.—In the case of a civil ac-
12 tion brought under subsection (a)(2), with respect to a
13 covered entity, the district court in which such action is
14 brought shall advance on its docket and expedite review
15 and disposition of such action.

16 (d) RULE OF CONSTRUCTION.—Nothing in this sec-
17 tion is intended to limit or replace available remedies
18 under the Americans with Disabilities Act of 1990 or any
19 other applicable law.

20 **SEC. 6. EFFECT ON OTHER LAWS.**

21 Nothing in this Act shall be construed to supersede
22 any provision of any State or local law that provides great-
23 er rights to qualified individuals with respect to organ
24 transplants than the rights established under this Act.