

118TH 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) 34 States have crafted State-level policy to
11 prohibit organ transplant discrimination against in-
12 dividuals with disabilities. Federal action, however,
13 is required to protect individuals with disabilities
14 and to enforce existing law regardless of the State
15 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) In the national administration of organ allo-
4 cation in the United States, organs are transported
5 across State lines for transplantation procedures.

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

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

15 **SEC. 3. DEFINITIONS.**

16 In this Act:

17 (1) **AUXILIARY AIDS AND SERVICES.**—The term
18 “auxiliary aids and services” includes—

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

23 (B) qualified readers, taped texts, or other
24 effective methods of making visually delivered

1 materials available to individuals with a visual
2 impairment;

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

6 (D) supported decisionmaking services;
7 and

8 (E) acquisition or modification of equip-
9 ment or devices.

10 (2) COVERED ENTITY.—The term “covered en-
11 tity” means any licensed provider of health care
12 services (including licensed health care practitioners,
13 hospitals, nursing facilities, laboratories, inter-
14 mediate care facilities, psychiatric residential treat-
15 ment facilities, institutions for individuals with intel-
16 lectual or developmental disabilities, and prison
17 health centers), and any transplant hospital (as de-
18 fined in section 121.2 of title 42, Code of Federal
19 Regulations or a successor regulation), that—

20 (A) is in interstate commerce; or

21 (B) provides health care services in a man-
22 ner that—

23 (i) substantially affects or has a sub-
24 stantial relation to interstate commerce; or

1 (ii) includes use of an instrument (in-
2 cluding an instrument of transportation or
3 communication) of interstate commerce.

4 (3) DISABILITY.—The term “disability” has the
5 meaning given the term in section 3 of the Ameri-
6 cans with Disabilities Act of 1990 (42 U.S.C.
7 12102).

8 (4) HUMAN ORGAN.—The term “human organ”
9 has the meaning given the term in section 301(c) of
10 the National Organ Transplant Act (42 U.S.C.
11 274e(c)).

12 (5) MATCHING ENTITY.—The term “matching
13 entity” means an entity described in section 4.

14 (6) ORGAN TRANSPLANT.—The term “organ
15 transplant” means the transplantation or trans-
16 fusion of a donated human organ into the body of
17 another human for the purpose of treating a medical
18 condition.

19 (7) QUALIFIED INDIVIDUAL.—The term “quali-
20 fied individual” means an individual who, with or
21 without a support network, provision of auxiliary
22 aids and services, or reasonable modifications to
23 policies or practices, meets eligibility requirements
24 for the receipt of a human organ.

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

4 (A) communication with persons respon-
5 sible for supporting a qualified individual with
6 postsurgical or other care following an organ
7 transplant or related services, including support
8 with medication; and

9 (B) consideration, in determining whether
10 a qualified individual will be able to comply
11 with health requirements following an organ
12 transplant or receipt of related services, of sup-
13 port networks available to the qualified indi-
14 vidual, including family, friends, and providers
15 of home and community-based services, includ-
16 ing home and community-based services funded
17 through the Medicare or Medicaid program
18 under title XVIII or XIX, respectively, of the
19 Social Security Act (42 U.S.C. 1395 et seq.,
20 1396 et seq.), another health plan in which the
21 qualified individual is enrolled, or any program
22 or source of funding available to the qualified
23 individual.

1 (9) RELATED SERVICES.—The term “related
2 services” means services related to an organ trans-
3 plant that consist of—

4 (A) evaluation;

5 (B) counseling;

6 (C) treatment, including postoperative
7 treatment, and care;

8 (D) provision of information; and

9 (E) any other service recommended or re-
10 quired by a physician.

11 (10) SECRETARY.—The term “Secretary”
12 means the Secretary of Health and Human Services.

13 (11) SUPPORTED DECISION MAKING.—The term
14 “supported decision making” means the use of a
15 support person to assist a qualified individual in
16 making health care decisions, communicate informa-
17 tion to the qualified individual, or ascertain a quali-
18 fied individual’s wishes. Such term includes—

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

23 (B) permitting the individual to designate
24 a person of the individual’s choice for the pur-
25 poses of supporting that individual in commu-

1 nating, processing information, or making
2 health care decisions;

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

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

17 (E) providing health information in a for-
18 mat that is readily understandable by the indi-
19 vidual; and

20 (F) working with a court-appointed guard-
21 ian or other person responsible for making
22 health care decisions on behalf of the individual,
23 to ensure that the individual is included in deci-
24 sions involving the health care of the individual

1 and that health care decisions are in accordance
2 with the individual’s own expressed interests.

3 (12) SUPPORT NETWORK.—The term “support
4 network” means, with respect to a qualified indi-
5 vidual, one or more people who are—

6 (A) selected by the qualified individual or
7 by the qualified individual and the guardian of
8 the qualified individual, to provide assistance to
9 the qualified individual or guidance to that
10 qualified individual in understanding issues,
11 making plans for the future, or making complex
12 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 quali-
17 fied individual.

18 **SEC. 4. PROHIBITION OF DISCRIMINATORY POLICY.**

19 An entity who receives a contract under section 372
20 of the Public Health Service Act (42 U.S.C. 274) to match
21 human organs and individuals, and otherwise carry out
22 the functions described in subsection (b) of that section,
23 shall not issue policies, recommendations, or other memo-
24 randa that would prohibit, or otherwise hinder, a qualified

1 individual's access to an organ transplant solely on the
2 basis of that individual's disability.

3 **SEC. 5. PROHIBITION OF DISCRIMINATION.**

4 (a) IN GENERAL.—Subject to subsection (b), a cov-
5 ered entity may not, solely on the basis of a qualified indi-
6 vidual's disability—

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

9 (2) deny the individual an organ transplant or
10 related services;

11 (3) refuse to refer the individual to an organ
12 transplant center or other related specialist for the
13 purpose of receipt of an organ transplant or other
14 related services; or

15 (4) refuse to place the individual on an organ
16 transplant waiting list.

17 (b) EXCEPTION.—

18 (1) IN GENERAL.—

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

1 dividualized evaluation of the potential recipi-
2 ent, to be medically significant to the receipt of
3 the organ transplant or related services, as the
4 case may be.

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

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

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

1 fications would fundamentally alter the nature of such
2 policies or practices.

3 (d) CLARIFICATIONS.—

4 (1) NO DENIAL OF SERVICES BECAUSE OF AB-
5 SENCE OF AUXILIARY AIDS AND SERVICES.—For
6 purposes of this section, a covered entity shall take
7 such steps as may be necessary to ensure that a
8 qualified individual with a disability is not denied a
9 procedure associated with the receipt of an organ
10 transplant or related services, because of the absence
11 of auxiliary aids and services, unless the covered en-
12 tity can demonstrate that taking such steps would
13 fundamentally alter the nature of the procedure
14 being offered or would result in an undue burden on
15 the entity.

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

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

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

1 et seq.) including the provisions added to such
2 Act by the ADA Amendments Act of 2008, sec-
3 tion 504 of the Rehabilitation Act of 1973 (29
4 U.S.C. 794), section 1557 of the Patient Pro-
5 tection and Affordable Care Act (42 U.S.C.
6 18116), or any other applicable law.

7 (e) ENFORCEMENT.—

8 (1) IN GENERAL.—Any individual who alleges
9 that a qualified individual was subject to a violation
10 of this section by a covered entity—

11 (A) may bring a claim regarding the alle-
12 gation to the Office for Civil Rights of the De-
13 partment of Health and Human Services, for
14 expedited resolution; and

15 (B) whether or not such a claim is brought
16 under subparagraph (A) or a violation is found
17 pursuant to subparagraph (A), may bring a
18 civil action in a district court of the United
19 States for injunctive or other equitable relief,
20 including the relief described in paragraph (2),
21 against such covered entity to obtain compli-
22 ance of such covered entity with this section.

23 (2) RELIEF AVAILABLE.—The injunctive and
24 equitable relief available in a civil action brought

1 under paragraph (1)(B), with respect to a covered
2 entity, includes—

3 (A) requiring auxiliary aids and services to
4 be made available by the entity involved;

5 (B) requiring reasonable modifications to
6 policies or practices (including procedures) of
7 such entity; or

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

10 (3) EXPEDITED REVIEW.—In the case of a civil
11 action brought under paragraph (1)(B), with respect
12 to a covered entity, the district court in which such
13 action is brought shall advance on its docket and ex-
14 pedite review and disposition of such action.

15 (4) RULE OF CONSTRUCTION.—Nothing in this
16 subsection is intended to limit or replace available
17 remedies under the Americans with Disabilities Act
18 of 1990 (42 U.S.C. 12101 et seq.) or any other ap-
19 plicable law.

20 **SEC. 6. APPLICATION TO EACH PART OF PROCESS.**

21 The provisions of this Act—

22 (1) that apply to an organ transplant, also
23 apply to the evaluation and listing of a qualified in-
24 dividual, and to the organ transplant and post-

1 organ-transplant treatment of such an individual;
2 and

3 (2) that apply to related services, also apply to
4 the process for receipt of related services by such an
5 individual.

6 **SEC. 7. EFFECT ON OTHER LAWS.**

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