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.

Be it enacted by the Senate and House of Representa-

tives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

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

SEC. 2. FINDINGS.

Congress finds the following:

(1) The Americans with Disabilities Act of 1990, section 504 of the Rehabilitation Act of 1973, and section 1557 of the Patient Protection and Af-
affordable Care Act prohibit discrimination against individuals with disabilities in organ transplantation and the allocation of organs.

(2) Despite those prohibitions, there are findings and cases that show, as is documented by the National Council on Disability and others, that individuals with disabilities are being denied organ transplants and related services based solely on the fact that those individuals have a disability.

(3) More than 25 States have crafted State-level policy to prohibit organ transplant discrimination against individuals with disabilities. Federal action, however, is required to protect individuals with disabilities and to enforce existing law regardless of the State in which they live.

(4) The current situation, with continuing cases of discrimination against individuals with disabilities, calls for further clarity by Congress about which actions constitute discrimination under current law, which entities are covered, and the remedies available to individuals experiencing potential discrimination.

(5) Licensed providers of health care services that provide organ transplants and related services in exchange for medical fees are engaging in an eco-
nomic transaction with patients that occurs in or
substantially impacts interstate commerce.

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

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

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

SEC. 3. DEFINITIONS.

In this Act:

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

(A) qualified interpreters or other effective
methods of making aurally delivered materials
available to individuals with a hearing impair-
ment;
(B) qualified readers, taped texts, or other effective methods of making visually delivered materials available to individuals with a visual impairment;

(C) information in a format that is accessible for individuals with a cognitive, neurological, developmental, or intellectual disability;

(D) supported decisionmaking services; and

(E) acquisition or modification of equipment or devices.

(2) COVERED ENTITY.—The term “covered entity” means—

(A) 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, that—

(i) is in interstate commerce; or

(ii) provides health care services in a manner that—
(I) substantially affects or has a substantial relation to interstate commerce; or

(II) includes use of an instrument (including an instrument of transportation or communication) of interstate commerce; or

(B) any transplant center or entity responsible for matching human organ donors to potential recipients that is in interstate commerce, or that provides the matching services in a manner described in subparagraph (A)(ii).

(3) Disability.—The term “disability” has the meaning given the term in section 3 of the Americans with Disabilities Act of 1990 (42 U.S.C. 12102).

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

(5) Organ Transplant.—The term “organ transplant” means the transplantation or transfusion of a donated human organ into the body of another human for the purpose of treating or curing a medical condition.
(6) QUALIFIED INDIVIDUAL.—The term “qualified individual” means an individual who, with or without a support network, provision of auxiliary aids and services, or reasonable modifications to policies or practices, meets eligibility requirements for the receipt of a human organ.

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

(A) communication with individuals responsible for supporting an individual with postsurgical or other care following an organ transplant or related services, including support with medication; and

(B) consideration, in determining whether an individual will be able to comply with health requirements following an organ transplant or receipt of related services, of support networks available to the individual, including family, friends, and providers of home and community-based services, including home and community-based services funded through the Medicare or Medicaid program under title XVIII or XIX, respectively, of the Social Security Act (42 U.S.C. 1395 et seq., 1396 et seq.), another health plan
in which the individual is enrolled, or any program or source of funding available to the individual.

(8) RELATED SERVICES.—The term “related services” means services related to an organ transplant that consist of—

(A) evaluation;

(B) counseling;

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

(D) provision of information; and

(E) any other service recommended or required by a physician.

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

(10) SUPPORTED DECISIONMAKING.—The term “supported decisionmaking” means the use of a support person to assist an individual in making health care decisions, communicate information to the individual, or ascertain an individual’s wishes. Such term includes—

(A) the inclusion of the individual’s attorney-in-fact or health care proxy, or any person of the individual’s choice, in communications about the individual’s health care;
(B) permitting the individual to designate a person of the individual's choice for the purposes of supporting that individual in communicating, processing information, or making health care decisions;

(C) providing auxiliary aids and services described in subparagraph (A), (B), (C), or (E) of paragraph (1) to facilitate the individual's ability to communicate and process health-related information, including providing use of assistive communication technology;

(D) providing health information to persons designated by the individual, consistent with the regulations promulgated under section 264(c) of the Health Insurance Portability and Accountability Act of 1996 (42 U.S.C. 1320d–2 note) and other applicable laws and regulations governing disclosure of health information;

(E) providing health information in a format that is readily understandable by the individual; and

(F) working with a court-appointed guardian or other individual responsible for making health care decisions on behalf of the individual,
to ensure that the individual is included in decisions involving the health care of the individual and that health care decisions are in accordance with the individual’s own expressed interests.

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

(A) selected by the person or by the person and the guardian of the person, to provide assistance to that person or guidance to that person in understanding issues, making plans for the future, or making complex decisions; and

(B) who may include the family members, friends, unpaid supporters, members of the religious congregation, and appropriate personnel at a community center, of or serving the person.

SEC. 4. PROHIBITION OF DISCRIMINATION.

(a) IN GENERAL.—Subject to subsection (b), a covered entity may not, solely on the basis of a qualified individual’s mental or physical disability—

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

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

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

(5) decline insurance coverage for the individual for any procedure associated with the receipt of an organ transplant or for related services, which procedure or services, respectively, would be covered under such insurance for such individual if not for the disability of the individual.

(b) Exception.—

(1) In general.—

(A) Medically significant disabilities.—Notwithstanding subsection (a), a covered entity may take a qualified individual’s physical or mental disability into account when making a health care treatment or coverage recommendation or decision, solely to the extent that the disability has been found by a physician, following an individualized evaluation of
the potential recipient, to be medically significant to the receipt of the organ transplant or related services, as the case may be.

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

(2) CLARIFICATION.—If a qualified individual has the necessary support network to provide a reasonable assurance that the individual will be able to comply with health requirements following an organ transplant or receipt of related services, as the case may be, the individual’s inability to independently comply with those requirements may not be construed to be medically significant for purposes of paragraph (1).

(c) REASONABLE MODIFICATIONS.—A covered entity shall make reasonable modifications to policies or practices (including procedures) of such entity if such modifications are necessary to make an organ transplant or related services available to qualified individuals with disabilities, unless the entity can demonstrate that making such modifications would fundamentally alter the nature of such policies or practices.
(d) Clarifications.—

(1) No denial of services because of absence of auxiliary aids and services.—A covered entity shall take such steps as may be necessary to ensure that a qualified individual with a disability is not denied a procedure associated with the receipt of an organ transplant or related services, and insurance coverage for the individual is not declined for a procedure or services described in section 4(a)(5), 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 procedure or services being offered or would result in an undue burden on the entity.

(2) Compliance with other law.—Nothing in this Act shall be construed—

(A) to prevent a covered entity from providing organ transplants or related services at a level that is greater than the level that is required by this section; or

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

(3) Application to each part of process.—The provisions of this section apply to each part of the organ transplant process and the process for receipt of related services.

SEC. 5. ENFORCEMENT.

(a) In General.—Any individual who alleges that a qualified individual was subject to a violation of section 4 by a covered entity—

(1) may bring a claim regarding the allegation to the Office for Civil Rights of the Department of Health and Human Services, for expedited resolution; and

(2) whether or not such a claim is brought under paragraph (1) or a violation is found pursuant to paragraph (1), may bring a civil action in a district court of the United States for injunctive or other equitable relief, including the relief described in subsection (b), against such covered entity to obtain compliance of such covered entity with such section.
(b) RELIEF AVAILABLE.—The injunctive and equitable relief available in a civil action brought under subsection (a)(2), with respect to a covered entity, includes—

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

(2) requiring reasonable modifications to policies or practices (including procedures) of such entity; or

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

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

(d) RULE OF CONSTRUCTION.—Nothing in this section is intended to limit or replace available remedies under the Americans with Disabilities Act of 1990 or any other applicable law.

SEC. 6. EFFECT ON OTHER LAWS.

Nothing in this Act shall be construed to supersede any provision of any State or local law that provides greater rights to qualified individuals with respect to organ transplants than the rights established under this Act.