

117TH CONGRESS
1ST SESSION

H. R. 1235

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

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 23, 2021

Ms. HERRERA BEUTLER (for herself and Ms. PORTER) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To prohibit discrimination on the basis of mental or physical disability in cases of anatomical gifts and 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 as follows:

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

1 Act (ACA) prohibit discrimination against individ-
2 uals with disabilities in organ transplantation and
3 the rationing of organs.

4 (2) Despite these protections, there are findings
5 and cases that show that individuals with disabilities
6 are being denied organ transplants and related serv-
7 ices solely based on the fact that they have a dis-
8 ability, as is documented by the National Council on
9 Disability and others.

10 (3) Sixteen States have crafted state level policy
11 to prohibit organ transplant discrimination against
12 individuals with disabilities, however, Federal action
13 is required to protect Americans with disabilities and
14 to enforce existing law regardless of the state in
15 which they live.

16 (4) Continuing cases of discrimination against
17 individuals with disabilities calls for further clarity
18 by Congress to which actions constitute discrimina-
19 tion within the existing legal context, which entities
20 are covered, and the remedies available to individ-
21 uals experiencing potential discrimination.

22 (5) Licensed providers of health care services
23 who perform organ transplants and related services
24 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 for U.S. organ allocation with organs being
5 transported across state lines for transplantation
6 procedures.

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

11 (8) The existence of arbitrary discrimination
12 against individuals with disabilities in organ trans-
13 plantation and related services burdens the flow of
14 organs through legal channels of interstate com-
15 merce.

16 (9) Congress is empowered to regulate and pro-
17 tect the instrumentalities of interstate commerce,
18 persons, or things in interstate commerce, even
19 though the threat may come only from intrastate ac-
20 tivities.

21 (10) Congress' commerce authority includes the
22 power to regulate those activities having substantial
23 relation to interstate commerce and activities that
24 substantially affect interstate commerce.

1 (11) Nothing in this bill shall be construed to
2 limit or replace the scope of obligations imposed by
3 the Americans with Disabilities Act, section 504 of
4 the Rehabilitation Act of 1973, section 1557 of the
5 Affordable Care Act, or any other applicable law.

6 **SEC. 3. DEFINITIONS.**

7 For purposes of this Act:

8 (1) ANATOMICAL GIFT.—The term “anatomical
9 gift” means a donation of all or part of a human
10 body that takes effect after the death of the donor
11 for the purpose of transplantation or transfusion.

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

14 (A) qualified interpreters or other effective
15 methods of making aurally delivered materials
16 available to individuals with hearing impair-
17 ments;

18 (B) qualified readers, taped texts, or other
19 effective methods of making visually delivered
20 materials available to individuals with visual im-
21 pairments;

22 (C) provision of information in a format
23 that is accessible for individuals with cognitive,
24 neurological, developmental, or intellectual dis-
25 abilities;

1 (D) provision of supported decision-making
2 services; and

3 (E) acquisition or modification of equip-
4 ment or devices.

5 (3) COVERED ENTITY.—The term “covered en-
6 tity” means—

7 (A) any licensed provider of health care
8 services, including licensed health care practi-
9 tioners, hospitals, nursing facilities, labora-
10 tories, intermediate care facilities, psychiatric
11 residential treatment facilities, institutions for
12 individuals with intellectual or developmental
13 disabilities, and prison health centers; or

14 (B) any entity responsible for matching
15 anatomical gift donors to potential recipients.

16 (4) DISABILITY.—The term “disability” has the
17 same meaning give such term in section 4 of the
18 Americans with Disabilities Act of 1990.

19 (5) ORGAN TRANSPLANT.—The term “organ
20 transplant” means the transplantation or trans-
21 fusion of a part of a human body into the body of
22 another for the purpose of treating or curing a med-
23 ical condition.

24 (6) QUALIFIED INDIVIDUAL.—The term “quali-
25 fied individual” means an individual who, with or

1 without a support network, provision of auxiliary
2 aids and services, or reasonable modifications to
3 policies or practices, meets eligibility requirements
4 for the receipt of an anatomical gift.

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

8 (A) communication with individuals re-
9 sponsible for supporting an individual with
10 postsurgical and post-transplantation care, in-
11 cluding medication; and

12 (B) consideration of support networks
13 available to the individual, including family,
14 friends, and home and community-based serv-
15 ices, including home and community-based serv-
16 ices funded through medicaid, medicare, an-
17 other health plan in which the individual is en-
18 rolled, or any program or source of funding
19 available to the individual, in determining
20 whether the individual is able to comply with
21 posttransplant medical requirements.

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

24 (9) SUPPORTED DECISION MAKING.—The term
25 “supported decision making” means the use of a

1 support person to assist an individual in making
2 medical decisions, communicate information to the
3 individual, or ascertain an individual's wishes. Such
4 term may include—

5 (A) the inclusion of the individual's attor-
6 ney-in-fact, health care proxy, or any person of
7 the individual's choice in communications about
8 the individual's medical care;

9 (B) permitting the individual to designate
10 a person of their choice for the purposes of sup-
11 porting that individual in communicating, proc-
12 essing information, or making medical deci-
13 sions;

14 (C) providing auxiliary aids and services to
15 facilitate the individual's ability to communicate
16 and process health-related information, includ-
17 ing use of assistive communication technology;

18 (D) providing information to persons des-
19 igned by the individual, consistent with the
20 provisions of the Health Insurance Portability
21 and Accountability Act of 1996, (4 U.S.C. 13
22 et seq.), and other applicable laws and regula-
23 tions governing disclosure of health informa-
24 tion;

1 (E) providing health information in a for-
2 mat that is readily understandable by the indi-
3 vidual; and

4 (F) working with a court-appointed guard-
5 ian or other individual responsible for making
6 medical decisions on behalf of the individual, to
7 ensure that the individual is included in deci-
8 sions involving the health care of the individual
9 and that medical decisions are in accordance
10 with the individual's own expressed interests.

11 (10) SUPPORT NETWORK.—The term “support
12 network” means, with respect to a person, one or
13 more individuals selected by the person or by the
14 person and the guardian of the person, to provide
15 assistance to that person or guidance to that person
16 in understanding issues, making plans for the fu-
17 ture, or making complex decisions, including the per-
18 son's family, friends, unpaid supporters, religious
19 congregations, and community centers.

20 **SEC. 4. PROHIBITION OF DISCRIMINATION.**

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

24 (1) deem such individual ineligible to receive an
25 anatomical gift or organ transplant;

1 (2) deny such individual medical or related
2 organ transplantation services, including evaluation,
3 surgery, counseling, and postoperative treatment and
4 care;

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

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

13 (5) decline insurance coverage for such indi-
14 vidual for any procedure associated with the receipt
15 of an anatomical gift, including post-transplantation
16 care if such procedure would be covered under such
17 coverage for such individual if not for the disability
18 of the individual.

19 (b) EXCEPTION.—

20 (1) IN GENERAL.—Notwithstanding subsection
21 (a), a covered entity may take an individual's dis-
22 ability into account when making treatment or cov-
23 erage recommendations or decisions, solely to the ex-
24 tent that the physical or mental disability has been
25 found by a physician, following an individualized

1 evaluation of the potential recipient, to be medically
2 significant to the provision of the anatomical gift.
3 The previous sentence shall not be treated as requir-
4 ing referrals or recommendations for, or the per-
5 formance of, medically inappropriate organ trans-
6 plants.

7 (2) CLARIFICATION.—If an individual has the
8 necessary support system to provide reasonable as-
9 surance that the individual will comply with
10 posttransplant medical requirements, the individual’s
11 inability to independently comply with those require-
12 ments may not be deemed to be medically significant
13 for purposes of paragraph (1).

14 (c) REASONABLE MODIFICATIONS.—A covered entity
15 shall make reasonable modifications to policies, practices,
16 or procedures of such entity if such modifications are nec-
17 essary to make services such as transplantation-related
18 counseling, information, coverage, or treatment available
19 to qualified individuals with disabilities, unless the entity
20 can demonstrate that making such modifications would
21 fundamentally alter the nature of such services.

22 (d) CLARIFICATIONS.—

23 (1) A covered entity shall take such steps as
24 may be necessary to ensure that no qualified indi-
25 vidual with a disability is denied services such as

1 transplantation-related counseling, information, cov-
2 erage, or treatment because of the absence of auxil-
3 iary aids and services, unless the entity can dem-
4 onstrate that taking such steps would fundamentally
5 alter the nature of the services being offered or
6 would result in an undue burden.

7 (2) A covered entity shall otherwise comply with
8 the requirements of titles II and III of the Ameri-
9 cans with Disabilities Act of 1990 and the Ameri-
10 cans with Disabilities Act Amendments Act of 2008.

11 (3) The provisions of this section apply to each
12 part of the organ transplant process.

13 **SEC. 5. ENFORCEMENT.**

14 (a) IN GENERAL.—Any individual with a claim, with
15 respect to a covered entity, to be (or to have been) subject
16 to discrimination in violation of section 3—

17 (1) may bring such a claim to the Office for
18 Civil Rights of the Department of Health and
19 Human Services for expedited resolution; and

20 (2) whether or not such a claim is brought
21 under paragraph (1) or a violation is found pursuant
22 to paragraph (1), may bring a civil action before the
23 appropriate Federal court for injunctive or other eq-
24 uitable relief, including the relief described in sub-

1 section (b), against such covered entity to enforce
2 compliance of such covered entity with such section.

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

6 (1) requiring auxiliary aids or services to be
7 made available by such entity;

8 (2) requiring the modification of a policy, prac-
9 tice, or procedure of such entity; or

10 (3) requiring facilities of such entity be made
11 readily accessible and usable.

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

17 (d) RULE OF CONSTRUCTION.—Nothing in this sec-
18 tion is intended to limit or replace available remedies
19 under the Americans with Disabilities Act of 1990 and
20 the Americans with Disabilities Act Amendments Act of
21 2008 or any other applicable law.

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