

116TH CONGRESS
2D SESSION

H. R. 8981

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

IN THE HOUSE OF REPRESENTATIVES

DECEMBER 16, 2020

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. 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

body that takes effect after the death of the donor
for the purpose of transplantation or transfusion.

(2) 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 hearing impair-
ments;

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

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

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

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

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

(A) any licensed provider of health care
services, including licensed health care practi-
tioners, hospitals, nursing facilities, labora-

1 tories, intermediate care facilities, psychiatric
2 residential treatment facilities, institutions for
3 individuals with intellectual or developmental
4 disabilities, and prison health centers; or

5 (B) any entity responsible for matching
6 anatomical gift donors to potential recipients.

7 (4) DISABILITY.—The term “disability” has the
8 same meaning given such term in section 4 of the
9 Americans with Disabilities Act of 1990.

10 (5) ORGAN TRANSPLANT.—The term “organ
11 transplant” means the transplantation or trans-
12 fusion of a part of a human body into the body of
13 another for the purpose of treating or curing a med-
14 ical condition.

15 (6) QUALIFIED INDIVIDUAL.—The term “quali-
16 fied individual” means an individual who, with or
17 without a support network, provision of auxiliary
18 aids and services, or reasonable modifications to
19 policies or practices, meets eligibility requirements
20 for the receipt of an anatomical gift.

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

24 (A) communication with individuals re-
25 sponsible for supporting an individual with

1 postsurgical and post-transplantation care, in-
2 cluding medication; and

3 (B) consideration of support networks
4 available to the individual, including family,
5 friends, and home and community-based serv-
6 ices, including home and community-based serv-
7 ices funded through medicaid, medicare, an-
8 other health plan in which the individual is en-
9 rolled, or any program or source of funding
10 available to the individual, in determining
11 whether the individual is able to comply with
12 posttransplant medical requirements.

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

15 (9) SUPPORTED DECISION MAKING.—The term
16 “supported decision making” means the use of a
17 support person to assist an individual in making
18 medical decisions, communicate information to the
19 individual, or ascertain an individual’s wishes. Such
20 term may include—

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

1 (B) permitting the individual to designate
2 a person of their choice for the purposes of sup-
3 porting that individual in communicating, proc-
4 essing information, or making medical deci-
5 sions;

6 (C) providing auxiliary aids and services to
7 facilitate the individual's ability to communicate
8 and process health-related information, includ-
9 ing use of assistive communication technology;

10 (D) providing information to persons des-
11 ignated by the individual, consistent with the
12 provisions of the Health Insurance Portability
13 and Accountability Act of 1996 (4 U.S.C. 13 et
14 seq.), and other applicable laws and regulations
15 governing disclosure of health information;

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

19 (F) working with a court-appointed guard-
20 ian or other individual responsible for making
21 medical decisions on behalf of the individual, to
22 ensure that the individual is included in deci-
23 sions involving the health care of the individual
24 and that medical decisions are in accordance
25 with the individual's own expressed interests.

1 (10) SUPPORT NETWORK.—The term “support
2 network” means, with respect to a person, one or
3 more individuals selected by the person or by the
4 person and the guardian of the person, to provide
5 assistance to that person or guidance to that person
6 in understanding issues, making plans for the fu-
7 ture, or making complex decisions, including the per-
8 son’s family, friends, unpaid supporters, religious
9 congregations, and community centers.

10 **SEC. 3. PROHIBITION OF DISCRIMINATION.**

11 (a) IN GENERAL.—Subject to subsection (b), a cov-
12 ered entity may not, solely on the basis of a qualified indi-
13 vidual’s mental or physical disability—

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

16 (2) deny such individual medical or related
17 organ transplantation services, including evaluation,
18 surgery, counseling, and postoperative treatment and
19 care;

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

23 (4) refuse to place an individual on an organ
24 transplant waiting list, or placement of the indi-
25 vidual at a lower-priority position on the list than

1 the position at which the individual would have been
2 placed if not for the disability of the individual; or

3 (5) decline insurance coverage for such indi-
4 vidual for any procedure associated with the receipt
5 of an anatomical gift, including post-transplantation
6 care if such procedure would be covered under such
7 coverage for such individual if not for the disability
8 of the individual.

9 (b) EXCEPTION.—

10 (1) IN GENERAL.—Notwithstanding subsection
11 (a), a covered entity may take an individual's dis-
12 ability into account when making treatment or cov-
13 erage recommendations or decisions, solely to the ex-
14 tent that the physical or mental disability has been
15 found by a physician, following an individualized
16 evaluation of the potential recipient, to be medically
17 significant to the provision of the anatomical gift.
18 The previous sentence shall not be treated as requir-
19 ing referrals or recommendations for, or the per-
20 formance of, medically inappropriate organ trans-
21 plants.

22 (2) CLARIFICATION.—If an individual has the
23 necessary support system to provide reasonable as-
24 surance that the individual will comply with
25 posttransplant medical requirements, the individual's

1 inability to independently comply with those require-
2 ments may not be deemed to be medically significant
3 for purposes of paragraph (1).

4 (c) REASONABLE MODIFICATIONS.—A covered entity
5 shall make reasonable modifications to policies, practices,
6 or procedures of such entity if such modifications are nec-
7 essary to make services such as transplantation-related
8 counseling, information, coverage, or treatment available
9 to qualified individuals with disabilities, unless the entity
10 can demonstrate that making such modifications would
11 fundamentally alter the nature of such services.

12 (d) CLARIFICATIONS.—

13 (1) A covered entity shall take such steps as
14 may be necessary to ensure that no qualified indi-
15 vidual with a disability is denied services such as
16 transplantation-related counseling, information, cov-
17 erage, or treatment because of the absence of auxil-
18 iary aids and services, unless the entity can dem-
19 onstrate that taking such steps would fundamentally
20 alter the nature of the services being offered or
21 would result in an undue burden.

22 (2) A covered entity shall otherwise comply with
23 the requirements of titles II and III of the Ameri-
24 cans with Disabilities Act of 1990 and the Ameri-
25 cans with Disabilities Act Amendments Act of 2008.

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

3 **SEC. 4. ENFORCEMENT.**

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

7 (1) may bring such a claim to the Office for
8 Civil Rights of the Department of Health and
9 Human Services for expedited resolution; and

10 (2) whether or not such a claim is brought
11 under paragraph (1) or a violation is found pursuant
12 to paragraph (1), may bring a civil action before the
13 appropriate Federal court for injunctive or other eq-
14 uitable relief, including the relief described in sub-
15 section (b), against such covered entity to enforce
16 compliance of such covered entity with such section.

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

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

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

24 (3) requiring facilities of such entity be made
25 readily accessible and usable.

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

6 (d) RULE OF CONSTRUCTION.—Nothing in this sec-
7 tion is intended to limit or replace available remedies
8 under the Americans with Disabilities Act of 1990 and
9 the Americans with Disabilities Act Amendments Act of
10 2008 or any other applicable law.

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