118TH CONGRESS
2d Session
HOUSE OF REPRESENTATIVES
REPORT
118–507

CHARLOTTE WOODWARD ORGAN TRANSPLANT DISCRIMINATION PREVENTION ACT

MAY 14, 2024.—Committed to the Committee of the Whole House on the State of the Union and ordered to be printed

Mrs. RODGERS of Washington, from the Committee on Energy and Commerce, submitted the following

R E P O R T

[To accompany H.R. 2706]

The Committee on Energy and Commerce, to whom was referred the bill (H.R. 2706) to prohibit discrimination on the basis of mental or physical disability in cases of organ transplants, having considered the same, reports favorably thereon with an amendment and recommends that the bill as amended do pass.

CONTENTS

The amendment is as follows:

Strike all after the enacting clause and insert the following:

SECTION 1. SHORT TITLE.

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

SEC. 2. DEFINITIONS.

In this Act:

(1) AUXILIARY AIDS AND SERVICES.—The term "auxiliary aids and services" has the meaning given the term in section 4 of the Americans with Disabilities Act of 1990 (42 U.S.C. 12103).

(2) COVERED ENTITY.—The term "covered entity" means 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), and any transplant hospital (as defined in section 121.2 of title 42, Code of Federal Regulations or a successor regulation), that—

(A) is in interstate commerce; or

(B) 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.

(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 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 persons responsible for supporting a qualified individual with postsurgical or other care following an organ transplant or related services, including support with medication;

(B) consideration, in determining whether a qualified individual will be able to comply with health requirements following an organ transplant or receipt of related services, of support networks available to the qualified 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 qualified individual is enrolled, or any program or source of funding available to the qualified individual; and

(C) the use of supported decision-making, when needed, by a qualified 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) SUPPORTED DECISION-MAKING.—The term "supported decision-making" means the use of a support person to assist a qualified individual in making health care decisions, communicate information to the qualified individual, or ascertain a qualified 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 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 person 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.

(10) SUPPORT NETWORK.—The term "support network" means, with respect to a qualified individual, one or more people who are—

(A) selected by the qualified individual or by the qualified individual and the guardian of the qualified individual, to provide assistance to the qualified individual or guidance to that qualified individual 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 qualified individual.

SEC. 3. PROHIBITION OF DISCRIMINATORY POLICY.

The board of directors described in section 372(b)(1)(B) of the Public Health Service Act (42 U.S.C. 274(b)(1)(B)) shall not issue policies, recommendations, or other memoranda that would prohibit, or otherwise hinder, a qualified individual's access to an organ transplant solely on the basis of that individual's disability.

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 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; or

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

(b) EXCEPTION.—

(1) IN GENERAL.—

(A) MEDICALLY SIGNIFICANT DISABILITIES.—Notwithstanding subsection (a), a covered entity may take a qualified individual's 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 qualified individual will be able to comply with health requirements following an organ transplant or receipt of related services, as the case may be, the qualified 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.—For purposes of this section, 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, because of the absence of auxiliary aids and services, unless the covered entity can demonstrate that taking such steps would fundamentally alter the nature of the procedure being offered or would result in an undue burden on the entity.

(2) COMPLIANCE WITH OTHER LAW.—Nothing in this section 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 Act by the ADA Amendments Act of 2008, section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794), section 1557 of the Patient Protection and Affordable Care Act (42 U.S.C. 18116), or any other applicable law.

(e) ENFORCEMENT.—

(1) IN GENERAL.—Any individual who alleges that a qualified individual was subject to a violation of this section by a covered entity may bring a claim regarding the allegation to the Office for Civil Rights of the Department of Health and Human Services, for expedited resolution, as appropriate.

(2) RULE OF CONSTRUCTION.—Nothing in this subsection is intended to limit or replace available remedies under the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.) or any other applicable law.

SEC. 5. APPLICATION TO EACH PART OF PROCESS.

The provisions of this Act—

(1) that apply to an organ transplant, also apply to the evaluation and listing of a qualified individual, and to the organ transplant and post-organ-transplant treatment of such an individual; and

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

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.

PURPOSE AND SUMMARY

H.R. 2706 prohibits health care providers and other entities from denying or restricting an individual's access to organ transplants solely on the basis of the individual's disability, except in limited circumstances.

BACKGROUND AND NEED FOR LEGISLATION

According to the National Council on Disability, individuals with disabilities are often denied equal access to organ transplants based solely on disability status. The denials are usually based on assumptions that these individuals' lives are of poorer quality than individuals without disabilities and on misinterpretations regarding the ability of these individuals to comply with postoperative care.[1] Existing federal laws, the Americans with Disabilities Act of 1990, the Rehabilitation Act of 1973, and the Patient Protection and Affordable Care Act, prohibit organ transplant centers from discriminating on the basis of disability.[2] [3] [4] However, there is limited enforcement and a lack of federal guidance to ensure patients are protected. Some states have laws banning organ transplant discrimination, but the state patchwork can lead to further confusion, and disability-based discrimination in the organ transplant system continues to occur. For instance, an infant with down syndrome in Florida needed a heart transplant due to a congenital heart defect. The infant was denied a heart transplant by three physicians and

[1] National Council on Disability, Organ Transplant Discrimination Against People with Disabilities, Part of the Bioethics and Disability Series, September 25, 2019.

[2] Public Law 101–336, Americans with Disabilities Act of 1990.

[3] Public Law 93–112, Rehabilitation Act of 1973.

[4] Public Law 111–148, Patient Protection and Affordable Care Act.

tragically passed away.[5] H.R. 2706 will clarify that individuals with disabilities shall not be denied an organ transplant or related services, based solely on the individual's disability and includes an expedited review and enforcement mechanism through the Department of Health and Humans Services Office of Civil Rights.

COMMITTEE ACTION

On February 14, 2024, the Subcommittee on Health held a hearing on H.R. 2706. The title of the hearing was "Legislative Proposals to Support Patients and Caregivers." The Subcommittee received testimony from:

- Andy Shih, PhD, Chief Science Officer, Autism Speaks;
- Corey Feist, JD, MBA, Co-Founder and CEO, Dr. Lorna Breen Heroes' Foundation;
- Joanne Pike, DrPH, President and CEO, Alzheimer's Association;
- Gordon Tomaselli, MD, Former President, American Heart Association; Marilyn and Stanley M. Katz Dean, Emeritus and Professor of Medicine, Albert Einstein College of Medicine; Adjunct Professor of Medicine, Johns Hopkins University School of Medicine;
- Michelle Whitten, President, CEO, and Co-Founder, Global Down Syndrome Foundation;
- Randy Strozyk, President, American Ambulance Association; and,
- Christina Annunziata, MD, PhD, Senior Vice President of Extramural Discovery Science, American Cancer Society.

On March 12, 2024, the Subcommittee on Health met in open markup session and forwarded H.R. 2706, as amended, to the full Committee by voice vote.

On March 20, 2024, the full Committee on Energy and Commerce met in open markup session and ordered H.R. 2706, as amended, favorably reported to the House by a record vote of 46 yeas and 0 nays.

COMMITTEE VOTES

Clause 3(b) of rule XIII requires the Committee to list the record votes on the motion to report legislation and amendments thereto. The following reflects the record votes taken during the Committee consideration:

[5] WCJB, Ocala couple inspires NCFL Congresswoman to push forward bill for those with disabilities.

COMMITTEE ON ENERGY AND COMMERCE
118TH CONGRESS
ROLL CALL VOTE # 9

BILL: H.R. 2706, Charlotte Woodward Organ Transplant Discrimination Prevention Act

AMENDMENT: A motion by Chair Rodgers to order H.R. 2706 favorably reported to the House, as amended (Final Passage).

DISPOSITION: **AGREED TO**, by a roll call vote of 46 yeas to 0 nays.

REPRESENTATIVE	YEAS	NAYS	PRESENT	REPRESENTATIVE	YEAS	NAYS	PRESENT
Rep. Rodgers	X			Rep. Pallone	X		
Rep. Burgess	X			Rep. Eshoo	X		
Rep. Latta	X			Rep. DeGette	X		
Rep. Guthrie	X			Rep. Schakowsky	X		
Rep. Griffith	X			Rep. Matsui	X		
Rep. Bilirakis	X			Rep. Castor	X		
Rep. Bucshon	X			Rep. Sarbanes	X		
Rep. Hudson				Rep. Tonko			
Rep. Walberg	X			Rep. Clarke	X		
Rep. Carter	X			Rep. Cárdenas	X		
Rep. Duncan	X			Rep. Ruiz	X		
Rep. Palmer	X			Rep. Peters	X		
Rep. Dunn	X			Rep. Dingell	X		
Rep. Curtis	X			Rep. Veasey	X		
Rep. Lesko	X			Rep. Kuster			
Rep. Pence	X			Rep. Kelly	X		
Rep. Crenshaw	X			Rep. Barragán	X		
Rep. Joyce	X			Rep. Blunt Rochester			
Rep. Armstrong	X			Rep. Soto	X		
Rep. Weber				Rep. Craig	X		
Rep. Allen	X			Rep. Schrier	X		
Rep. Balderson	X			Rep. Trahan	X		
Rep. Fulcher	X			Rep. Fletcher	X		
Rep. Pfluger	X						
Rep. Harshbarger	X						
Rep. Miller-Meeks	X						
Rep. Cammack	X						
Rep. Obernolte	X						

03/20/2024

OVERSIGHT FINDINGS AND RECOMMENDATIONS

Pursuant to clause 2(b)(1) of rule X and clause 3(c)(1) of rule XIII, the Committee held a hearing and made findings that are reflected in this report.

NEW BUDGET AUTHORITY, ENTITLEMENT AUTHORITY, AND TAX EXPENDITURES

Pursuant to clause 3(c)(2) of rule XIII, the Committee finds that H.R. 2706 would result in no new or increased budget authority, entitlement authority, or tax expenditures or revenues.

CONGRESSIONAL BUDGET OFFICE ESTIMATE

Pursuant to clause 3(c)(3) of rule XIII, at the time this report was filed, the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974 was not available.

FEDERAL MANDATES STATEMENT

The Committee adopts as its own the estimate of Federal mandates prepared by the Director of the Congressional Budget Office pursuant to section 423 of the Unfunded Mandates Reform Act.

STATEMENT OF GENERAL PERFORMANCE GOALS AND OBJECTIVES

Pursuant to clause 3(c)(4) of rule XIII, the general performance goal or objective of this legislation is to prohibit health care practices that discriminate against individuals with a disability during the organ transplant process.

DUPLICATION OF FEDERAL PROGRAMS

Pursuant to clause 3(c)(5) of rule XIII, no provision of H.R. 2706 is known to be duplicative of another Federal program, including any program that was included in a report to Congress pursuant to section 21 of Public Law 111 139 or the most recent Catalog of Federal Domestic Assistance.

RELATED COMMITTEE AND SUBCOMMITTEE HEARINGS

Pursuant to clause 3(c)(6) of rule XIII, the following related hearing was used to develop or consider H.R. 2706:

- On February 14, 2024, the Subcommittee on Health held a hearing on H.R. 2706. The title of the hearing was "Legislative Proposals to Support Patients and Caregivers." The Subcommittee received testimony from:
  - Andy Shih, PhD, Chief Science Officer, Autism Speaks;
  - Corey Feist, JD, MBA, Co-Founder and CEO, Dr. Lorna Breen Heroes' Foundation;
  - Joanne Pike, DrPH, President and CEO, Alzheimer's Association;
  - Gordon Tomaselli, MD, Former President, American Heart Association; Marilyn and Stanley M. Katz Dean, Emeritus and Professor of Medicine, Albert Einstein College of Medicine; Adjunct Professor of Medicine, Johns Hopkins University School of Medicine;

- Michelle Whitten, President, CEO, and Co-Founder, Global Down Syndrome Foundation;
- Randy Strozyk, President, American Ambulance Association; and,
- Christina Annunziata, MD, PhD, Senior Vice President of Extramural Discovery Science, American Cancer Society.

COMMITTEE COST ESTIMATE

Pursuant to clause 3(d)(1) of rule XIII, the Committee adopts as its own the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974. At the time this report was filed, the estimate was not available.

EARMARK, LIMITED TAX BENEFITS, AND LIMITED TARIFF BENEFITS

Pursuant to clause 9(e), 9(f), and 9(g) of rule XXI, the Committee finds that H.R. 2706 contains no earmarks, limited tax benefits, or limited tariff benefits.

ADVISORY COMMITTEE STATEMENT

No advisory committees within the meaning of section 5(b) of the Federal Advisory Committee Act were created by this legislation.

APPLICABILITY TO LEGISLATIVE BRANCH

The Committee finds that the legislation does not relate to the terms and conditions of employment or access to public services or accommodations within the meaning of section 102(b)(3) of the Congressional Accountability Act.

SECTION-BY-SECTION ANALYSIS OF THE LEGISLATION

Section 1. Short title

Section 1 provides that the Act may be cited as the "Charlotte Woodward Organ Transplant Discrimination Prevention Act".

Section 2. Definitions

Section 2 provides definitions for various terms used throughout the bill text.

Section 3. Prohibition of discriminatory policy

Section 3 prohibits the Board of Directors of the Organ Procurement and Transplantation Network from issuing policies that would prohibit a qualified individual from accessing an organ transplant solely on the basis of that individual's disability.

Section 4. Prohibition of discrimination

Section 4 prohibits a covered entity from determining an individual is ineligible to receive an organ transplant, denying an individual an organ, refusing to refer an individual to a transplant center, or refusing to place the individual on the transplant waitlist based solely on the individual's disability, except in certain circumstances. It also requires the Office of Civil Rights within the Department of Health and Human Services to expedite claims allowed under this Act, providing for stronger enforcement.

Section 5. Application to each part of process

Section 5 clarifies that certain provisions of this Act also apply to the evaluation and listing of qualified individuals, post-organ-transplant treatment of such an individual, and the process of receipt of related services.

Section 6. Effect on other laws

Section 6 clarifies that nothing in this Act shall be construed to supersede any provision of State or local law that provides further protections to individuals with disabilities.

CHANGES IN EXISTING LAW MADE BY THE BILL, AS REPORTED

This legislation does not amend any existing Federal statute.

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