

HOUSE OF REPRESENTATIVES STAFF ANALYSIS

BILL #: CS/HB 1179 Nondiscrimination in Organ Transplants

SPONSOR(S): Health Market Reform Subcommittee, Fischer

TIED BILLS: **IDEN./SIM. BILLS:** SB 1556

REFERENCE	ACTION	ANALYST	STAFF DIRECTOR or BUDGET/POLICY CHIEF
1) Health Market Reform Subcommittee	14 Y, 0 N, As CS	Morris	Calamas
2) Health & Human Services Committee	18 Y, 0 N	Morris	Calamas

SUMMARY ANALYSIS

Organ and tissue donation is the process of surgically removing an organ or tissue from one person (the donor) and transplanting it into another person (the recipient). Transplantation in such cases is necessary because the recipient's organ has failed or has been damaged by disease or injury.

The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 prohibit discrimination on the basis of disability. HB 1179 prohibits discrimination in access to anatomical gifts and organ transplants for individuals with disabilities. Health insurance policies and health maintenance organization contracts would also be prohibited from denying coverage for an organ transplant solely on the basis of an insured's or subscriber's disability.

The bill prohibits covered entities from taking specific actions against an individual with a developmental or intellectual disability who is eligible to receive an anatomical gift (human body parts donated after death for use in transplants, therapy, research, or education) based solely on the fact that they have a disability. Covered entities include health care practitioners, health care facilities, and any other entity responsible for potential recipients of anatomical gifts.

The bill requires covered entities to make reasonable accommodations in their policies, practices, or procedures, when necessary, to allow a patient with a disability access to services unless it is demonstrated that making the modification would fundamentally alter the nature of the services.

The bill provides injunctive relief for a qualified individual who is affected by violations of these provisions committed by a covered entity.

The bill has an indeterminate, insignificant, negative fiscal impact on AHCA and DOH.

The bill provides an effective date of July 1, 2020.

FULL ANALYSIS

I. SUBSTANTIVE ANALYSIS

A. EFFECT OF PROPOSED CHANGES:

Present Situation

Organ Donation

Organ and tissue donation is the process of surgically removing an organ or tissue from one person (the donor) and transplanting it into another person (the recipient). Transplantation in such cases is necessary because the recipient's organ has failed or has been damaged by disease or injury. Transplantable organs include the kidneys, liver, heart, lungs, pancreas and intestine.¹ Transplantable tissue include skin used as a temporary dressing for burns, serious abrasions and other exposed areas; heart valves used to replace defective valves; tendons used to repair torn ligaments on knees or other joints; veins used in cardiac by-pass surgery; corneas used to restore sight; and bone used in orthopedic surgery to facilitate healing of fractures or prevent amputation.²

A single person can save up to eight lives through organ donation, and dozens more lives may be improved through tissue donation.³ While most organ and tissue donations occur after the donor has died, some organs, including a kidney or part of a liver or lung, and tissues can be donated while the donor is alive.⁴ There are about as many living donors every year as there are deceased donors.⁵

Despite advances in medicine and technology, and increased awareness of organ donation and transplantation, more donors are needed to meet the demand for transplants.⁶ As of January 2020, there are more than 112,000 children and adults⁷, including over 5,000 Floridians.⁸ Over 39,000 organ transplants were performed in 2019 with organs from more than 19,000 donors.⁹

Organ donation is not defined in Florida Statutes. Instead, statutes refer to anatomical gifts, which are human body parts donated after death for use in transplants, therapy, research, or education.¹⁰

Organ Donation and Transplant Process

Established by the National Organ Transplant Act of 1984, the Organ Procurement and Transplantation Network (OPTN) is a public-private partnership that links all professionals involved in the nation's donation and transplant system.¹¹ The United Network for Organ Sharing (UNOS), a private, non-profit organization based in Richmond, Virginia, serves as the OPTN under contract with the U.S. Department of Health and Human Resources.¹² UNOS coordinates how donor organs are matched and allocated to patients on the waiting list.¹³ Non-profit, federally designated organ procurement organizations (OPOs) work closely with UNOS, hospitals, and transplant centers to facilitate the organ

¹ Donate Life Florida, *Frequently Asked Questions*, <https://www.donateliflorida.org/categories/donation/> (last visited Feb. 9, 2020).

² Id.

³ Id.

⁴ U.S. Government Information on Organ Donation and Transplantation, U.S. Department of Health & Human Services, *How Organ Donation Works*, <https://organdonor.gov/about/process.html> (last visited Feb. 9, 2020).

⁵ Id.

⁶ Organ Procurement and Transplantation Network, U.S. Department of Health & Human Services, <https://optn.transplant.hrsa.gov/> (last visited Feb. 9, 2020).

⁷ Id.

⁸ Supra, note 1.

⁹ Id.

¹⁰ S. 765.511(2), F.S.

¹¹ U.S. Department of Health and Human Services, *Organ Procurement and Transplantation Network – About the OPTN*, <https://optn.transplant.hrsa.gov/governance/about-the-optn/> (last visited Feb. 9, 2020).

¹² Id.

¹³ U.S. Government Information on Organ Donation and Transplantation, U.S. Department of Health & Human Services, *The Organ Transplant Process*, <https://organdonor.gov/about/process/transplant-process.html> (last visited Feb. 9, 2020).

donation and transplantation process,¹⁴ including conducting a thorough medical and social history of the potential donor to help determine the suitability of his or her organs for transplantation.¹⁵

The donation process begins when a person, or their family if the person was not already a registered donor before brain death, decides to become an organ donor. After brain death is declared, the donor's body is kept functioning by artificial means, such as a ventilator support.¹⁶ Specially-trained medical practitioners from the OPO evaluates the patient to determine if they are medically suitable to donate their organs.¹⁷ If the patient is suitable, their organs are surgically removed and sent to the transplant hospitals where transplant candidates are waiting.¹⁸ The deceased donor's blood type, height, weight, the hospital zip code, and other data are entered into UNOS' national computer system to begin the organ allocation process.¹⁹

Transplant candidates are patients on the transplant waiting list. A patient is usually referred to a transplant center by their physician for placement on the waiting list.²⁰ The transplant center's transplant teams, composed of transplant physicians, surgeons and other practitioners, perform a medical evaluation of the patient.²¹ Each transplant center sets its own criteria to help determine if a patient is a good or bad candidate.²² Typical criteria includes weight, age, and health history. If the patient is a bad candidate, the patient is not placed on the waiting list, but can try to get placed on the waiting list at another transplant center or be reconsidered by the same transplant center if their condition improves (for example, losing weight as directed).²³ If a patient is determined to be a good candidate for an organ transplant, they are placed on the waiting list by the transplant center and wait for an organ to become available. Candidates are able to be placed on the waiting list at more than one transplant center.²⁴

When an organ becomes available, the OPO will query the OPTN database for a match based on a variety of factors, including relative location of the recipient to the organ, blood type, weight, and age.²⁵ If a match is found, the transplant surgeon will evaluate the potential recipient of the organ transplant and make a determination on whether the potential recipient is medically suitable.²⁶ The transplant team only has one hour to make this determination.²⁷ If suitable, the organ is transported to the transplant center where the recipient is waiting and the transplant surgery is performed, otherwise the potential recipient remains on the waiting list.

Medical urgency, blood type, size of the organ, whether the recipient is an adult or a child, relative distance between the donor and the recipient, and the degree of immune-system match between the

¹⁴ Donate Life Florida, *Organ Procurement Organizations and Transplant Centers*, <https://www.donateliflorida.org/local-resources/transplant-centers/> (last visited Feb. 9, 2020).

¹⁵ Organ Procurement and Transplantation Network, U.S. Department of Health & Human Services, *The Basic Path of Donation*, <https://optn.transplant.hrsa.gov/learn/about-donation/the-basic-path-of-donation/> (last visited Feb. 9, 2020).

¹⁶ Donate Life Florida, *Frequently Asked Questions - Donation*, <https://www.donateliflorida.org/categories/donation/> (last visited Feb. 9, 2020).

¹⁷ UNOS, *Deceased Donation*, <https://unos.org/transplant/deceased-donation/> (last visited Feb. 9, 2020).

¹⁸ *Id.*

¹⁹ *Id.*

²⁰ Health Resources & Services Administration, *The Organ Transplant Process*, <https://www.organdonor.gov/about/process/transplant-process.html#list> (last visited Feb. 9, 2020).

²¹ U.S. Department of Health and Human Services, *The Transplant Team*, <https://optn.transplant.hrsa.gov/learn/about-transplantation/the-transplant-team/> (last visited Feb. 9, 2020).

²² UNOS, *Frequently Asked Questions – What do I need to do to be considered for a transplant?*, <https://unos.org/transplant/frequently-asked-questions/> (last visited Feb. 9, 2020).

²³ UNOS Transplant Living, *Frequently Asked Questions – Are there age limits or medical conditions that rule out organ transplantation?*, <https://transplantliving.org/before-the-transplant/frequently-asked-questions/> (last visited Feb. 9, 2020).

²⁴ UNOS, *What Every Patient Needs to Know* (2019), <https://unos.org/wp-content/uploads/unos/WEPNTK.pdf> (last visited Feb. 9, 2020).

²⁵ Health Resources & Services Administration, *Matching Donors and Recipients*, <https://www.organdonor.gov/about/process/matching.html#criteria> (last visited Feb. 9, 2020). See also Health Resources & Services Administration, *Find Your Local Organ Procurement Organization*, <https://www.organdonor.gov/awareness/organizations/local-opo.html> (last visited Feb. 9, 2020).

²⁶ UNOS Transplant Living, *Frequently Asked Questions – How does the matching process work?* <https://transplantliving.org/before-the-transplant/frequently-asked-questions/> (last visited Feb. 9, 2020).

²⁷ *Id.*

donor and the recipient can impact who is prioritized for an organ for transplant.²⁸ Transplant centers may also include other factors in prioritization, such as the ability to take care of oneself after surgery, attend post operation doctor appointments, and stay current with medications.²⁹

Disability

The term “disability” as enacted in the federal Americans with Disabilities Act (ADA)³⁰ means a physical or mental impairment that substantially limits one or more major life activities such as caring for oneself, performing manual tasks, seeing, walking, hearing, standing, learning, thinking, and communicating. The definition also includes individuals with a previous record of such an impairment and, under certain circumstances, who are generally regarded as having such an impairment. Types of disabilities include ambulatory, hearing, cognitive, vision, independent living, and self-care.³¹ Disabilities can be related to conditions present at birth, associated with developmental conditions, related to an injury, or associated with a longstanding condition.³² Individuals with disabilities are a diverse group of people with a wide range of needs.³³

In addition to physical impairments, mental impairments can significantly interfere the everyday activities of life. Anxiety disorders, mood disorders, and schizophrenia disorders are all types of mental impairments. Mental disorders are among the most common causes of disability.³⁴ Additionally, individuals with intellectual disabilities, characterized by significant limitations in both intellectual functioning and adaptive behavior, suffer disproportionately from substance use problems.³⁵

Approximately 12.7% [over 40 million people] of the U.S. population has a disability.³⁶ Florida’s disability population is estimated at 13.6% (over 2.8 million people).

Organ Transplant Discrimination

The ADA and Section 504 of the federal Rehabilitation Act of 1973 prohibit discrimination on the basis of disability. The National Council on Disability (NCD) produced a report relating to discrimination against individuals with disabilities in the organ transplant process.³⁷ The NCD examined applicable federal and state laws, the disability-related policies of various transplant centers, and policies of the OPTN. The NCD found that:

- Discrimination continues to occur in the nine states³⁸ that have enacted laws expressly prohibiting such discrimination;
- Disabilities unrelated to a person’s need for an organ transplant generally have little or no impact on the likelihood that the transplant will be successful; and
- Many organ transplant centers³⁹ have policies that bar or caution against placing people with HIV, psychiatric disabilities, or intellectual and developmental disabilities on the waiting list to receive an organ transplant because of concern the patient may not be able to take care of themselves after transplant surgery.

²⁸ UNOS, *How we match organs*, <https://unos.org/transplant/how-we-match-organs/> (last visited Feb. 9, 2020).

²⁹ *Supra*, note 24.

³⁰ 42 U.S.C. 12102

³¹ United States Census Bureau, *Types of Disabilities*, <https://www.census.gov/library/visualizations/2019/comm/types-of-disabilities.html> (last visited Feb. 9, 2020).

³² Centers for Disease Control and Prevention, *Disability Health Overview*, <https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html> (last visited Feb. 9, 2020).

³³ *Id.*

³⁴ Office of Disease Prevention and Health Promotion, *Mental Health and Mental Disorders*, <https://www.healthypeople.gov/2020/topics-objectives/topic/mental-health-and-mental-disorders> (last visited Feb. 9, 2020).

³⁵ Shawna L. Carroll Chapman and Li-Tzy Wu, *Substance Abuse among Individuals with Intellectual Disabilities*, (July 2012) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3328139/> (last visited Feb. 9, 2020).

³⁶ United States Census Bureau 2018 American Community Survey, *Disability Characteristics*, <https://data.census.gov/> (last visited Feb. 9, 2020).

³⁷ National Council on Disability, *Organ Transplant Discrimination Against People with Disabilities*, (Sept. 25, 2019) https://ncd.gov/sites/default/files/NCD_Organ_Transplant_508.pdf (last visited Feb. 9, 2020).

³⁸ California, Delaware, Kansas, Maryland, Massachusetts, New Jersey, Ohio, Oregon, and Pennsylvania.

³⁹ *Id.* at 55, including The University of Florida Health’s transplant center and Tampa General Hospital.

Taking care of oneself post-transplant involves quite a bit of effort. Transplant recipients usually need to take an array of medications or prevent the body from rejecting the transplanted organ sometimes for life. Some medications may need to be taken several times a day and others only on certain days.⁴⁰ Dosages may be adjusted weekly or every few days in order to find the best combination for maximum benefits and minimum side effects. Managing medications can become complex and confusing.⁴¹ Doctors monitor transplant patients for years after transplant surgery and laboratory tests become routine.⁴² Living a healthy lifestyle that includes eating a balanced diet and exercise plays a key role in maintaining health after a transplant.⁴³

Overall, long-term survival rates after transplants have increased since 1970.⁴⁴ In order for continued improvement in survival rates, long-term management and approaches post operation must continue to improve.⁴⁵

Patient Protection and Affordable Care Act

The Patient Protection and Affordable Care Act (PPACA)⁴⁶ imposed extensive requirements on health insurers and health insurance policies relating to required benefits, rating and underwriting standards, required review of rate increases, and other requirements.⁴⁷ Among its sweeping changes to the U.S. health care system are requirements for health insurers to make coverage available to all individuals and employers, without exclusions for preexisting conditions and without basing premiums on any health-related factors.⁴⁸

Many of the changes in the PPACA apply to individual and small group markets, except those plans that have grandfathered status under the law.⁴⁹ For example, the PPACA requires coverage offered in the individual and small group markets to provide the certain categories of services, called essential health benefits.⁵⁰

Also, the PPACA requires that premiums for individual and small group policies may vary only by:⁵¹

- Age, up to a maximum ratio of 3 to 1. This means that the rates for older adults cannot be more than three times greater than the rates for younger adults.
- Tobacco, up to a maximum ratio of 1.5 to 1.
- Geographic rating area.
- Whether coverage is for an individual or a family.

The PPACA prohibits an insurer from establishing rules for eligibility based on any of the following health status-related factors: health status, medical condition, claims experience, receipt of health care, medical history, genetic information, disability, evidence of insurability (including conditions arising out

⁴⁰ Health Resources & Services Administration, *The Organ Transplant Process – After Your Transplant*, <https://www.organdonor.gov/about/process/transplant-process.html#list> (last visited Feb. 9, 2020).

⁴¹ Id.

⁴² Id.

⁴³ Id.

⁴⁴ Abbas Rana, MD and Elizabeth Louise Godfrey, BSBE, *Outcomes in Solid-Organ Transplantation: Success and Stagnation*, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6379008/> (last visited Feb. 9, 2020).

⁴⁵ Id.

⁴⁶ Patient Protection and Affordable Care Act (PPACA), Pub. L. No. 111-148.

⁴⁷ Most of the insurance regulatory provisions in PPACA amend Title XXVII of the Public Health Service Act (PHSA), 42 U.S.C. 300gg et seq.

⁴⁸ Under PPACA, the prohibition on preexisting condition exclusion refers to the fact that health insurance companies cannot refuse coverage or charge higher premiums to those who have a “pre-existing condition” — that is, a health problem that existed before the date that health coverage starts. Prior to passage of the PPACA, employers and insurers could exclude coverage for pre-existing conditions for a period of time if an individual had not maintained continuous insurance coverage, unless prohibited by state law.

⁴⁹ For an insured plan, grandfathered health plan coverage is group or individual coverage in which an individual was enrolled on March 23, 2010, subject to conditions for maintaining grandfathered status as specified by law and rule. See PPACA s. 1251; 42 U.S.C. s. 18011.

⁵⁰ PPACA s. 1302; 42 U.S.C. 300gg-6.

⁵¹ PPACA s. 1201; 42 U.S.C. 300gg.

of domestic violence), or any other health-status related factor deemed appropriate by the U.S. Department of Health and Human Services.⁵²

State Regulation of Health Insurance

The regulatory oversight of health insurance is generally reserved to the states, except when explicitly preempted by federal law. In Florida, the Office of Insurance Regulation (OIR) is responsible for all activities concerning insurers and other risk bearing entities, including licensing, rates, policy forms, market conduct, claims, issuance of certificates of authority, solvency, viatical settlements, premium financing, and administrative supervision, as provided under the insurance code.⁵³

All health insurance policies issued in the state of Florida, with the exception of certain self-insured policies⁵⁴, must meet certain requirements that are detailed throughout the Florida Insurance Code. Chapter 627, F.S., sets parameters and requirements for health insurance policies and ch. 641, F.S., provides requirements for insurance policies issued by health maintenance organizations (HMOs). At a minimum, insurance policies must specify premium rates, services covered, and effective dates. Insurers must document the time when a policy takes effect and the period during which the policy remains in effect.⁵⁵

Effect of the Bill

HB 1179 prohibits discrimination in access to anatomical gifts and organ transplants for individuals with disabilities. Health insurance policies, health maintenance organizations, and group health policies would also be prohibited from denying coverage for a transplant based on a disability.

The bill prohibits covered entities from taking specific actions against an individual with a developmental or intellectual disability who is eligible to receive an anatomical gift based solely on the fact that they have a disability. The bill prohibits certain actions by licensed health care practitioners, health care facilities, and any other entity responsible for potential recipients of anatomical gifts. Such entities may not consider a qualified individual ineligible to receive an anatomical gift or organ transplant, deny medical or other services related to an organ transplant, refuse to refer the individual to an OPO or a specialist for a transplant evaluation, refuse to place the individual on the waiting list, or give the individual a lower priority position on the waiting list.

When making treatment or coverage recommendations for a patient, the bill allows a covered entity to take a disability into account if, after an evaluation, a physician finds the disability to be medically significant to the receipt of an anatomical gift. Additionally, a covered entity may not consider the patient's inability to comply with post-transplant medical requirements as medically significant if they have a support system to assist with such compliance.

The bill requires covered entities to make reasonable accommodations in their policies, practices, or procedures, when necessary, to allow a patient with a disability access to services unless it is demonstrated that making the modification would fundamentally alter the nature of the services. The accommodations include communicating with the people responsible for supporting the patient with their post-transplant care and the consideration of support networks available to the patient.

Under the bill, a covered entity must take the necessary steps to ensure that a person with a disability is not denied services due to the absence of auxiliary aids and services, including interpreters for those with hearing impairments, effective methods of delivering information to people with visual impairments, and supported decision making services. Such services may include the use of a support person to help make medical decisions and communicate information, disclosing health information to a person

⁵² PPACA s. 1201; 42 U.S.C. s. 300gg-4.

⁵³ s. 20.121(3)(a)1., F.S. The OIR's commissioner is the agency head for purposes of final agency action, and its rulemaking body is the Financial Services Commission (the Governor and the Cabinet).

⁵⁴ 29 U.S.C. 18 § 1001 et seq. ERISA regulates certain self-insured plans, which represent approximately 50 percent of the insureds in Florida. These plans cannot be regulated by state law.

⁵⁵ S. 627.413(1)(d), F.S.

designated by the patient, using a court appointed guardian or other legal representative who is authorized to make health care decisions on behalf of the patient, and any other aid or service that can be used to understandably convey information to the patient.

The bill provides injunctive or other equitable relief for a qualified individual who is affected by a violation of such provisions committed by a covered entity.

The bill expressly states that it may not be interpreted as requiring a covered entity to make a referral or recommendation for, or to perform, a medically inappropriate transplant.

The bill prohibits discrimination by insurers against individuals who are recipients of organ transplants. This prohibition includes issuers of fully-insured individual and group health plans, as well as HMOs. The bill does not require coverage of organ transplant services, but prohibits plans that do cover organ transplants from denying coverage for an organ transplant solely on the basis of a covered individual having a disability.

The bill provides an effective date of July 1, 2020.

B. SECTION DIRECTORY:

- Section 1:** Creates s. 765.523, F.S., relating to discrimination in access to anatomical gifts and organ transplants prohibited.
- Section 2:** Creates s. 627.64197, F.S., relating to nondiscrimination of coverage for organ transplants.
- Section 3:** Creates s. 627.65736, F.S., relating to nondiscrimination of coverage for organ transplants.
- Section 4:** Creates s. 641.31075, F.S., relating to nondiscrimination of coverage for organ transplants.
- Section 5:** Provides an effective date of July 1, 2020.

II. FISCAL ANALYSIS & ECONOMIC IMPACT STATEMENT

A. FISCAL IMPACT ON STATE GOVERNMENT:

1. Revenues:

None.

2. Expenditures:

The bill has an indeterminate, insignificant, negative fiscal impact on the Agency for Health Care Administration Division of Health Quality Assurance and the Department of Health Division of Medical Quality Assurance due to the investigation of complaints and enforcement relating to violations of any act proposed under this bill committed by a health care facility or a licensed health care practitioner. The impact can be absorbed within current resources.

The bill has an indeterminate, insignificant, negative fiscal impact on the Office of Insurance Regulation and the Agency for Health Care Administration due to the investigation of complaints and enforcement relating to violations of any act proposed under this bill committed by insurance companies and HMOs.

B. FISCAL IMPACT ON LOCAL GOVERNMENTS:

1. Revenues:

None.

2. Expenditures:

None.

C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:

None.

D. FISCAL COMMENTS:

None.

III. COMMENTS

A. CONSTITUTIONAL ISSUES:

1. Applicability of Municipality/County Mandates Provision:

Not applicable. The bill does not appear to affect county or municipal governments.

2. Other:

None.

B. RULE-MAKING AUTHORITY:

Current law contains sufficient rulemaking authority for AHCA to implement the provisions of this bill.

C. DRAFTING ISSUES OR OTHER COMMENTS:

None.

IV. AMENDMENTS/ COMMITTEE SUBSTITUTE CHANGES

On January 28, 2020, the Health Market Reform Subcommittee adopted an amendment that:

- Narrows the applicability of the bill to individuals with developmental or intellectual disabilities;
- Removes residential facilities for persons with developmental disabilities and institutional medical units in correctional facilities from the list of covered entities; and
- Makes technical and conforming changes.

The bill was reported favorably as a committee substitute.

The analysis is drafted to the committee substitute as passed by the Health Market Reform Subcommittee.