

Department of Legislative Services
Maryland General Assembly
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FISCAL AND POLICY NOTE

House Bill 1122 (Delegate Hill)
Rules and Executive Nominations

Public Health - Nondiscrimination in Access to Anatomical Gifts and Organ Transplantation

This emergency bill prohibits the discrimination against a potential recipient of any anatomical gift or organ transplant solely on the basis of an individual's disability, as defined in the federal Americans with Disabilities Act of 1990. The prohibition applies to each part of the organ transplant process.

Fiscal Summary

State Effect: Maryland Insurance Administration special fund revenues increase minimally in FY 2016 due to \$125 rate and form filings fees. Any increase in workload can be handled with existing resources. The bill's requirements can otherwise be handled with existing budget resources.

Local Effect: The provisions of the bill are not expected to materially affect local government finances or operations.

Small Business Effect: None.

Analysis

Bill Summary:

The bill defines specified terms related to the anatomical gift and organ transplantation process and individuals with disabilities. A "covered entity" is defined as (1) a licensed health care provider; (2) a health care facility; (3) a laboratory; (4) a State psychiatric hospital; (5) a State residential center; (6) an alternative living unit; (7) a group home; (8) an institutional medical unit in a correctional facility; (9) a health insurance carrier; or

(10) any entity responsible for matching an anatomical gift donor with potential recipients of the anatomical gift. A “qualified individual” is an individual who has a disability and meets the essential eligibility requirements for the receipt of an anatomical gift, with or without support networks available to the individual, the provision of auxiliary aids and services, or reasonable modifications to the policies or practices of a covered entity as specified.

The bill prohibits a covered entity, solely on the basis of an individual’s disability, from (1) considering a qualified individual ineligible to receive an anatomical gift or organ transplant; (2) denying medical and other services related to organ transplantation, including evaluation, surgery, counseling, and posttransplantation treatment and services; (3) refusing to refer the individual to a transplant center or a related specialist; (4) refusing to place a qualified individual on an organ transplant waiting list; (5) placing an otherwise qualified individual at a lower-priority position on an organ transplant waiting list; or (6) declining health insurance coverage for any procedure associated with the receipt of an anatomical gift, including posttransplantation care.

An individual’s disability may be taken into account when making treatment or coverage decisions to the extent that a disability is found to be medically significant. However, if an individual has the necessary support system to assist in complying with posttransplantation medical requirements, an individual’s inability to independently comply with such requirements may not be found to be medically significant. With specified exceptions, reasonable modifications must be made to policies, practices, and procedures, when necessary to make all services available to an individual with a disability.

If a covered entity violates the provisions of the bill, the affected individual can bring an action in the appropriate circuit court for injunctive or other equitable relief. The bill also requires a court to schedule a hearing as soon as possible for an action related to enforcement of the bill’s provisions. The court has to apply the same standards as would be applied in an action brought in federal court under the federal Americans with Disabilities Act.

The bill includes various findings of the General Assembly related to discrimination in the provision of anatomical gifts or organ transplants.

The bill may not be construed to require a referral or recommendation for, or perform, a medically inappropriate organ transplant.

Current Law: Existing State law focuses primarily on the donation of anatomical gifts and not on the recipient of those gifts. The allocation of organs and tissue to recipients is handled on the national level, as discussed below.

The Maryland Revised Uniform Anatomical Gift Act (Title 4, Subtitle 5 of the Estates and Trusts Article) governs donations of all or part of a human body (that take effect after the donor's death) for the purpose of transplantation, therapy, research, training, or education. Among other things, the Act specifies:

- who may make an anatomical gift during the life of a donor (taking effect after the donor's death) and how a donor may make a gift, including by a "document of gift," defined as a donor card or other record such as a statement or symbol on a driver's license, identification card, or donor registry;
- the classifications of individuals, in order of priority, who may make an anatomical gift of a donor's body or part after the donor's death;
- how an anatomical gift may be revoked or amended and how an individual may indicate a refusal to make an anatomical gift of the individual's body or part;
- the relation between, and priorities of, actions taken by the donor and other authorized persons, with respect to making, amending, revoking, or refusing an anatomical gift; and
- the resolution of conflicts between an advance directive and an anatomical gift.

The persons eligible to make an anatomical gift during the life of the donor include an adult donor; a minor who is emancipated or eligible to apply for a driver's license; an agent of a donor (unless prohibited by a power of attorney for health care or other record); a parent of a donor, if the donor is an unemancipated minor; or a guardian of a donor. Directions given by a person authorized to make, amend, revoke, or refuse to make an anatomical gift of a decedent's body or part must be recorded in the decedent's medical record.

In addition, the Act requires each hospital in the State to enter into an agreement or affiliation with a procurement organization.

Background:

Organ Donation and Transplantation in Maryland

There are two transplant centers located in the State: the University of Maryland Medical Center (UMMC) and Johns Hopkins Hospital. Both facilities qualify as covered entities under the definition included in the bill. Each center may establish its own criteria for acceptance and listing of potential recipients. Both centers accept referrals from physicians or other medical professionals as well as self-referrals by patients. Both centers require

potential recipients to undergo a transplantation evaluation prior to admission to the transplant program or inclusion on any waiting list.

The UMMC evaluation process includes a broad consultation session with potential recipients (also described as “candidates”) about all aspects of transplantation to help determine if transplant surgery is appropriate. This session includes a medical history, physical exam, and an education session. An interview is conducted by a specially trained transplant nurse and addresses (1) the entire transplant process, including entry into the program, surgery, discharge planning, and outpatient follow-up; (2) the waiting period and the national waiting list; (3) the expected results following surgery; and (4) the patient’s responsibilities for ongoing treatment.

At Johns Hopkins, all patients receive an initial evaluation by members of the transplant team, and potential recipients are asked to provide a list of all prescription, over-the-counter, and herbal medications, including name, dosage, and frequency of use. The potential recipient’s medical records and recent test results are also examined. Once all tests are completed, the transplant team reviews cases to determine transplant eligibility. The determination includes the results of the medical evaluation as well as other considerations, including (1) substance abuse (active substance abusers do not qualify for a transplant); (2) HIV status; (3) age; and (4) smoking. Patients with HIV may still be eligible for a transplant, though other criteria must be met.

The organ donor procurement program in the State is managed by the Living Legacy Foundation of Maryland (LLF), which coordinates with all hospitals in the State for the procurement of organs. In accordance with State and federal regulations, hospitals in Maryland must contact LLF when a patient dies or death is imminent. LLF reviews the potential donor’s medical status and assesses his or her potential suitability as a donor; as appropriate, a family services coordinator discusses donation options with the family.

If organ donation is authorized, LLF works collaboratively with the hospital staff to manage the critical care medical and nursing needs of the donor, while conducting further evaluation and testing to determine which organs are suitable for transplant. (A donor family does not incur any financial costs related to the evaluation and recovery of organs and tissues.) The medical information about the organ donor is sent to the United Network for Organ Sharing (UNOS), which operates a centralized computer system to match the donor’s characteristics to those of waiting recipients. UNOS allocates organs based on algorithms (which factor in blood type, severity of illness, time waiting, and distance between the donor hospital and potential recipient), but tissues are allocated based on medical need.

National Organ Donation and Transplantation Policies

UNOS is the private, nonprofit organization that manages the nation's organ transplant system under contract with the federal government. UNOS is involved in many aspects of the organ transplant and donation process, including (1) managing the national transplant waiting list and matching donors to recipients; (2) developing policies that make the best use of the limited supply of organs and give all patients a fair chance at receiving the organ they need, regardless of age, sex, ethnicity, religion, lifestyle, or financial/social status; (3) monitoring every organ match to ensure organ allocation policies are followed; (4) providing assistance to patients, family members, and friends; and (4) educating transplant professionals and the public.

The UNOS Organ Procurement and Transplantation Network (OPTN) Nondiscrimination Policy in Organ Allocation for offering organs specifies that “a candidate’s citizenship or residency status in the United States must not be considered when allocating deceased donor organs to candidates for transplantation.” The policy further states that “allocation of deceased donor organs must not be influenced positively or negatively by political influence, national origin, ethnicity, sex, religion, or financial status.” The policy does not incorporate reference to a candidate’s disability.

Some policies are effectively delegated to the individual transplant centers. For example, the OPTN Potential Candidate Screening Requirements permit HIV-positive individuals as organ candidates if permitted by the transplant hospital. Care of HIV-positive organ candidates and recipients should not deviate from general medical practice.

Prohibitions Against Discrimination in Anatomical Gifts and Organ Transplantation in Other States

California: AB 2861 of 1996 precludes a hospital, physician, surgeon, procurement organization, or other person from discriminating against potential recipients of any anatomical gift on the basis of that person’s physical or mental disabilities, as defined in the federal Americans with Disabilities Act of 1990. AB 2861 requires a court to give priority on its calendar to any action brought to seek any remedy authorized by law for purposes of enforcing compliance with the provisions of AB 2861.

New Jersey: P.L. 2013, Chapter 80, prohibits discrimination against a prospective organ transplant recipient solely on the basis of a physical or mental disability. The law specifically establishes that an individual who is a candidate to receive an anatomical gift must not be deemed ineligible solely based on the individual’s physical or mental disability, except to the extent that the physical or mental disability has been found by a physician or surgeon to be medically significant to the provision of the anatomical gift. If an individual has the necessary support system to assist with complying with post-

transplant medical requirements, the individual's inability to independently comply with those requirements cannot be deemed to be medically significant. The law also requires a court to give priority on its calendar to an action brought to seek any remedy authorized by any law.

Pennsylvania: House Bill 1474 of 2013 would have enacted provisions similar to the California and New Jersey laws. It was referred to the Pennsylvania House Judiciary Committee in June 2014, and no further action has been taken.

Organ Donation Rates in the United States

Although the rates of organ donor designation have increased in the United States, the need for transplants continues to outpace available organs. According to the U.S. Department of Health and Human Services (HHS), more than 120 million people in the United States have signed up to be an organ donor and an average of 79 people receive an organ transplant each day. However, HHS reports that 21 people die each day while on the waiting list for an organ and that, as of February 21, 2015, 123,231 Americans are waiting for an organ, 3,716 of whom are on the waiting list in Maryland.

According to the 2014 National Donor Designation Report Card from the organization Donate Life America, Maryland ranked twenty-eighth among states with a 54% donor designation share, which is the number of designated donors as a percentage of all state residents age 18 or older.

Additional Information

Prior Introductions: None.

Cross File: SB 792 (Senator Astle) - Finance.

Information Source(s): Department of Health and Mental Hygiene, Maryland Insurance Administration, Office of the Deaf and Hard of Hearing, Department of Disabilities, Judiciary (Administrative Office of the Courts), Department of Public Safety and Correctional Services, University of Maryland Medical System, Johns Hopkins Medicine, Donate Life America, Living Legacy Foundation, U.S. Department of Health and Human Services, Department of Legislative Services

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