SENATE BILL REPORT SB 5405

As Reported by Senate Committee On: Health & Long Term Care, February 8, 2019

Title: An act relating to nondiscrimination in access to organ transplants.

Brief Description: Concerning nondiscrimination in access to organ transplants.

Sponsors: Senators Padden, Randall, Zeiger, Fortunato, Billig, Wilson, C., Nguyen and Kuderer.

Brief History:

Committee Activity: Health & Long Term Care: 2/04/19, 2/08/19 [DPS].

Brief Summary of First Substitute Bill

 Prohibits health care providers from denying organ transplant services to an individual with a disability solely on the basis of the individual's disability.

SENATE COMMITTEE ON HEALTH & LONG TERM CARE

Majority Report: That Substitute Senate Bill No. 5405 be substituted therefor, and the substitute bill do pass.

Signed by Senators Cleveland, Chair; Randall, Vice Chair; O'Ban, Ranking Member; Becker, Dhingra, Frockt, Keiser and Van De Wege.

Staff: LeighBeth Merrick (786-7445)

Background: An organ transplant is a surgical operation to give a functioning human organ to someone with organ failure. The organ the person receives may be known as an anatomical gift and comes from someone who is living or has passed away. Health care providers refer individuals at risk or experiencing organ failure to an organ transplant center. The organ transplant center conducts extensive evaluations of the individual to determine if they meet the eligibility criteria to receive an organ transplant. The evaluations conducted on the individual include:

• medical testing to determine the level of organ failure, potential donor matches, and the individual's ability to tolerate surgery;

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- psychological testing to determine the individual's ability to follow pre- and posttransplant regimens, and manage addictive or harmful behaviors which may include drug testing; and
- financial testing to determine how the individual will pay for the transplant, and the medications, care, and procedures that may be required after the surgery.

The Americans with Disabilities Act (ADA) is a federal law that prohibits public accommodations, such as doctor's offices and hospitals, and state-run programs from discriminating against people with disabilities. The Rehabilitation Act is a federal law that prohibits federally-funded programs, such as Medicare and Medicaid providers, from discriminating against people with disabilities.

Summary of Bill (First Substitute): Health care providers are prohibited from using an individual's mental or physical disability as the sole reason for denying them access to organ transplant services. This includes using the individual's mental or physical disability as the sole purpose for:

- deeming the individual ineligible to receive an organ transplant or anatomical gift;
- denying the individual evaluation, surgery, counseling, and postoperative treatment and care;
- refusing to refer the individual to a transplant center or other related organ transplant specialty;
- refusing to place an individual on an organ transplant list, or placing the individual at a lower priority position; and
- declining insurance coverage for the organ transplant, including post transplant care.

A health care provider is permitted to take an individual's disability into account after a physician has conducted an individualized evaluation of the potential recipient, and has made a decision the disability would be medically significant to the individual receiving an organ transplant. An individual's inability to comply with post transplant medical requirements can not be deemed as medically significant if they have the necessary support system to assist them with compliance.

A health care provider must make reasonable modifications to their policies, practices, or procedures to make organ transplant services such as counseling, information, coverage, or treatment available to a qualified individual with a disability. A health care provider must ensure that no qualified individual with a disability is denied transplant-related counseling, information, coverage or treatment because of the absence of auxiliary aids and services. Auxiliary aids include effective methods of making aurally- or visually-delivered information available to individuals with hearing or visual impairments, or individuals with intellectual disabilities.

An individual who has been denied access to organ transplant services solely on the basis of their physical or mental disability may take civil action.

EFFECT OF CHANGES MADE BY HEALTH & LONG TERM CARE COMMITTEE (First Substitute):

• Modifies the Legislature's findings by removing the finding that individuals with mental and physical disabilities have been historically denied life-saving organ transplants, and adds that an individual's right to health care includes organ transplantation.

Appropriation: None.

Fiscal Note: Not requested.

Creates Committee/Commission/Task Force that includes Legislative members: No.

Effective Date: Ninety days after adjournment of session in which bill is passed.

Staff Summary of Public Testimony on Original Bill: The committee recommended a different version of the bill than what was heard. PRO: A study found that the majority of transplant centers consider an individual's intellectual or developmental disability when making decisions about organ transplant services. It is important that the state call attention to this specific issue, and protect people from being discriminated against so they can receive necessary health care. Other states have passed similar legislation. This bill references the ADA and helps implement it.

OTHER: Health care facilities providing organ transplant services have strict guidelines to ensure they comply with the ADA. The intent section makes it seem like organ transplant service providers are discriminating against individuals with disabilities and we would just ask for this to be clarified.

Persons Testifying: PRO: Senator Mike Padden, Prime Sponsor; Ashley Helsing, Director of Government Relations, National Down Syndrome Society; David Lord, Disability Rights Washington.

OTHER: Ian Goodhew, UW Medicine Health System; Chris Bandoli, citizen.

Persons Signed In To Testify But Not Testifying: No one.

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