# HOUSE BILL REPORT SSB 5405

# As Reported by House Committee On:

Health Care & Wellness

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

**Brief Description**: Concerning nondiscrimination in access to organ transplants.

**Sponsors**: Senate Committee on Health & Long Term Care (originally sponsored by Senators Padden, Randall, Zeiger, Fortunato, Billig, Wilson, C., Nguyen and Kuderer).

# **Brief History:**

#### **Committee Activity:**

Health Care & Wellness: 3/20/19, 3/27/19 [DPA].

# Brief Summary of Substitute Bill (As Amended by Committee)

• Prohibits disability-based discrimination against individuals regarding organ transplant services.

#### HOUSE COMMITTEE ON HEALTH CARE & WELLNESS

**Majority Report**: Do pass as amended. Signed by 14 members: Representatives Cody, Chair; Macri, Vice Chair; Schmick, Ranking Minority Member; Caldier, Assistant Ranking Minority Member; Chambers, Davis, DeBolt, Harris, Jinkins, Riccelli, Robinson, Stonier, Thai and Tharinger.

Staff: Jim Morishima (786-7191).

# **Background:**

Organ transplants are surgical procedures in which functioning human organs are transferred to persons experiencing organ failure. Donated organs (otherwise known as anatomical gifts) are matched with persons needing organs through organ procurement organizations and the United Network for Organ Sharing.

This analysis was prepared by non-partisan legislative staff for the use of legislative members in their deliberations. This analysis is not a part of the legislation nor does it constitute a statement of legislative intent.

House Bill Report - 1 - SSB 5405

Organ transplants are performed in organ transplant centers. Prior to a transplant, an organ transplant center evaluates the patient to ensure that the patient is suitable for the transplant. Criteria used by transplant centers can include medical history, physical examination, psychological examination, and compatibility tests.

Health care facilities are prohibited from discriminating against patients on the basis of disability by federal and state law, including the federal Americans with Disabilities Act, the federal Rehabilitation Act, and the state Law Against Discrimination.

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#### **Summary of Amended Bill:**

#### Discrimination Prohibitions.

A health care provider or entity responsible for matching anatomical gift donors and recipients may not, solely on the basis of a qualified individual's mental or physical disability:

- deem the individual ineligible to receive an anatomical gift or organ transplant;
- deny medical or related organ transplantation services;
- refuse to refer the individual to a transplant center or other related specialist for evaluation or organ transplantation;
- refuse to place an individual on an organ transplant waiting list;
- place an individual at a lower position on an organ transplant waiting list; or
- decline insurance coverage for any procedure associated with the receipt of the anatomical gift.

An entity may take a person's disability into account when making treatment or coverage recommendations or decisions to the extent that a physician has evaluated the person and found that his or her physical or mental disability is medically significant to the provision of the anatomical gift. A person's inability to comply with post-transplant medical requirements is not medically significant if he or she has the necessary support system to provide reasonable assurance that he or she will comply with those requirements.

A health care provider or entity responsible for matching anatomical gift donors and recipients must make reasonable modifications to policies, practices, or procedures, when necessary to make transplant-related services available to qualified individuals with disabilities, unless doing so would fundamentally alter the nature of the services. The provider or entity must also take necessary steps to ensure that no qualified individual with a disability is denied transplant-related services because of the absence of auxiliary aids and services, unless doing so would fundamentally alter the nature of the services being offered or would result in an undue burden.

The requirements imposed on health care providers or entities responsible for matching anatomical gift donors and recipients do not require referrals or recommendations for, or the performance of, medically inappropriate organ transplants.

#### Enforcement.

A person who has been subjected to prohibited discrimination may bring a civil action in a court of competent jurisdiction to enjoin further violations and recover costs of the suit, including reasonable attorneys' fees. The court must give such an action priority and proceed expeditiously with the action.

#### Definitions.

A qualified individual is defined as a person who meets the essential eligibility requirements for the receipt of an anatomical gift with or without available support networks, auxiliary aids and services, or reasonable modifications to policies or practices.

Auxiliary aids and services include effective methods of delivering materials to persons with hearing or vision impairments, provision of information in a format that is accessible for persons with cognitive, neurological, developmental, or intellectual disabilities, provision of supported decision-making services, and acquisition or modification of equipment or devices.

Reasonable modifications to policies or practices include communication with persons responsible for post-surgical and post-transplantation care and consideration of support networks available to the qualified individual.

Supported decision making means the use of a support person to assist a qualified individual in making decisions, communicate information to the individual, or ascertain the individual's wishes. Supported decision making includes the inclusion of any person chosen by the qualified individual (including an attorney or health care proxy), permitting the individual to designate a person to support the person to communicate, process information, or make medical decisions, providing auxiliary aids and services to facilitate the individual's ability to communicate and process health-related information, providing information to persons designated by the individual, providing health information that is readily understandable by the individual, and working with court-appointed guardians or other individuals responsible for making medical decisions on behalf of the individual to ensure that he or she is included in health care decisions and that medical decisions are in accordance with his or her expressed interests.

#### **Amended Bill Compared to Substitute Bill:**

The amended bill requires that an individual's support system provide reasonable assurance that he or she will comply with post-transplant medical requirements for purposes of determining the medical significance of his or her ability or inability to independently comply with post-transplant requirements.

Appropriation: None.

Fiscal Note: Available.

House Bill Report - 3 - SSB 5405

Effective Date of Amended Bill: The bill takes effect 90 days after adjournment of the session in which the bill is passed.

# **Staff Summary of Public Testimony:**

(In support) The majority of transplant centers consider a person's intellect or disability at least some of the time. For example, a person with Down syndrome was denied because their IQ was too low. People with disabilities deserve the same rights as everyone else. People often have strong support systems in place; no one does it on their own. People with disabilities should not be denied health care just because they rely on others for support. People with disabilities, such as autism, are treated differently by health providers and feel their lives are not valued. The federal Americans with Disabilities Act prohibits this type of discrimination, but a number of states have enacted laws like this one. This bill will not stop discrimination, but is a good start.

(Opposed) None.

**Persons Testifying**: Senator Padden, prime sponsor; Diana Stadden, The Arc of Washington; Eric Matthes; and Shaun Bickley, The Arc of King County.

Persons Signed In To Testify But Not Testifying: None.

House Bill Report - 4 - SSB 5405