(2nd reading) HB 119 Landgraf, et al.

SUBJECT: Prohibiting denial of organ transplant services based on disability

COMMITTEE: Public Health — favorable, without amendment

VOTE: 8 ayes — Klick, Guerra, Allison, Campos, Jetton, Oliverson, Price, Smith

0 nays

3 absent — Coleman, Collier, Zwiener

WITNESSES: For — Kathleen Kirwan-Haynie; (Registered, but did not testify: Bill

Kelly, City of Houston Mayor's Office; Shayne Woodard, Donate Life Texas; Dan Finch, Texas Medical Association; Jennifer Allmon, The

Texas Catholic Conference of Bishops; Thomas Parkinson)

Against — None

BACKGROUND: 42 U.S.C. sec. 12102 of the Americans with Disabilities Act (ADA)

defines an individual with a disability as a person who:

• has a physical or mental impairment that substantially limits one or more major life activities;

- has a record of such impairment; or
- is regarded as having such an impairment.

Sec. 12132 protects qualified individuals with disabilities from discrimination on the basis of disability in services, programs, and activities provided by state and local government entities. Sec. 12182 prohibits discrimination on the basis of disability in certain public places.

DIGEST: HB 119 would prohibit a health care provider from denying organ

transplant services to an individual solely based on the individual's disability, specify how the provider would have to modify procedures to accommodate the individual, and define several terms, including auxiliary

aids and services and supported decision making.

Prohibitions; permissions. HB 119 would prohibit a health care provider, solely based on an individual's disability, from:

- determining an individual was ineligible to receive an organ transplant;
- denying medical or other organ transplant services, including evaluation, surgery, counseling, and postoperative treatment;
- refusing to refer an individual to a transplant center or other specialist for evaluation or an organ transplant;
- refusing to place an individual on an organ transplant waiting list or placing the individual on a lower priority position; or
- declining insurance coverage for any organ transplant procedure, including post-transplant care.

The bill would require a health care provider to ensure that an individual with a disability was not denied services, including transplant-related counseling, information, coverage, or treatment, because auxiliary aids and services were absent. A health care provider would not have to meet this requirement if the provider could demonstrate that providing the transplant-related services with auxiliary aids and services present fundamentally would alter the provided transplant-related services or would impose an undue burden on the provider.

The bill would require a health care provider to make reasonable modifications in procedures as necessary to make transplant-related services available to an individual with a disability in certain circumstances. A health care provider would not have to meet this requirement if the provider could demonstrate that making modifications to the provided transplant-related services fundamentally would alter the nature of services. Reasonable modifications could include communicating with persons responsible for supporting an individual with postsurgical and post-transplant care, among other examples specified in the bill.

A health care provider could consider an individual's disability during treatment or coverage recommendations or decisions if a physician or

surgeon determined the disability was medically significant to the organ transplant. A health care provider could not consider an individual's inability to independently comply with post-transplant medical requirements as medically significant if the individual had the necessary support system to assist the individual in complying with the requirements.

The bill would authorize a regulatory agency that issued a license, certificate, or other authority to a health care provider to take disciplinary action against the provider that violated these provisions.

Definitions. The bill would define auxiliary aids and services to include:

- qualified interpreters, readers, and taped texts for individuals with hearing or visual impairments;
- information in a format accessible to individuals with cognitive, neurological, developmental, or intellectual disabilities; and
- supported decision-making services, among other services and equipment specified in the bill.

Supported decision making would mean the use of a support person to assist an individual in making medical decisions, communicate information to the individual, or ascertain an individual's wishes, including:

- allowing the individual's attorney-in-fact or agent under a medical power of attorney or other person selected by the individual to be included in the individual's medical care communication;
- permitting the individual to designate a person to support the individual in communicating, processing information, or making medical decisions;
- providing auxiliary aids and services to assist the individual in communicating and processing health-related information; and
- ensuring decisions on the individual's health care included the individual and the individual's expressed interests, among other provisions as specified in the bill.

Other provisions. The bill would require health care providers to comply with Titles II and III of the Americans with Disabilities Act.

By January 1, 2022, the executive commissioner of the Health and Human Services Commission would have to adopt rules necessary to implement the bill's provisions.

The bill would take effect September 1, 2021.

SUPPORTERS SAY: By prohibiting a health care provider from denying organ transplant services to an individual solely on the basis of the individual having a disability, HB 119 would strengthen anti-discrimination protections for Texans with special needs. Concerns have been raised about Texans being denied organ transplants because of a disability and because of health practitioners' perceptions about the individual's quality of life. Some individuals with disabilities who are otherwise active, well functioning adults require a medication regimen that can lead to organ failure. The bill would grant individuals with disabilities a chance that was equal to that of non-disabled individuals at receiving a potentially life-saving procedure.

HB 119 would establish sufficient authority to take disciplinary action against a health care provider if the provider violated certain provisions.

CRITICS SAY: By allowing a health care provider to deny organ transplantation if the provider demonstrated that auxiliary aids fundamentally would alter transplant services provided or would impose an undue burden on the provider, HB 119 would give excessive authority to health care providers in determining when they could refuse to provide organ transplant services with auxiliary services present to accommodate an individual with a disability. Without clearly defining an undue burden, the bill would provide insufficient protection to prevent denials of organ transplant services.

It would be better for the bill to reference an existing definition of supported decision-making in Estates Code sec. 1357.002 to maintain

consistency and avoid confusion.

OTHER CRITICS SAY: HB 119 should establish an expedited appeals process for individuals with disabilities whose requests for organ transplant services were denied based on their disability. An expedited appeals process would ensure individuals' discrimination claims were resolved in a timely manner and allow individuals with disabilities to access time-sensitive services.