### SESSION OF 2017

## SUPPLEMENTAL NOTE ON HOUSE BILL NO. 2343

#### As Recommended by House Committee on Children and Seniors

## Brief\*

HB 2343 would create new law regarding nondiscrimination in access to organ transplants for individuals with disabilities.

The bill would state the following findings and purpose:

- Mental or physical disability does not diminish an individual's right to health care;
- The federal Americans with Disabilities Act (ADA) prohibits discrimination against individuals with disabilities, yet many such individuals still experience discrimination in accessing critical health care services;
- In other states, individuals with disabilities have been denied lifesaving organ transplants based on assumptions their lives are less worthy, they are incapable of complying with post-transplantation medical requirements, or they lack adequate support systems to ensure compliance with posttransplantation medical requirements;
- Although organ transplant centers must consider medical and psychosocial criteria when determining if a patient is suitable to receive an organ transplant, transplant centers that participate in Medicare, the state program for medical

<sup>\*</sup>Supplemental notes are prepared by the Legislative Research Department and do not express legislative intent. The supplemental note and fiscal note for this bill may be accessed on the Internet at http://www.kslegislature.org

assistance, and other federally funded programs are required to use patient selection criteria that result in a fair and nondiscriminatory distribution of organs; and

• State residents in need of organ transplants are entitled to assurances they will not encounter discrimination on the basis of a disability.

The bill would define "covered entity" to include:

- A licensed health care provider, as defined in the Health Care Provider Insurance Availability Act;
- A medical care facility, as defined in the act governing standards for medical care facilities;
- A laboratory;
- A state psychiatric hospital, as defined in the Care and Treatment Act for Mentally III Persons;
- An adult care home, as defined in the act governing licensure of adult care home administrators;
- A group home, as defined in the statute governing planning and zoning of group homes;
- An institutional medical unit in a correctional facility; or
- Any entity responsible for potential recipients of the anatomical gift.

The bill would define "qualified individual" to mean an individual who has a disability (defined to have the meaning stated in the ADA) and meets the essential eligibility requirements for the receipt of an anatomical gift, with or without the 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, including certain modifications specified in the bill.

The bill would define "auxiliary aids and services" to include various methods of making aurally delivered materials available to individuals with hearing impairments and visually delivered materials available to individuals with visual impairments, as well as various supported decision-making services.

The bill would also define "anatomical gift" and "organ transplant."

The bill would prohibit a covered entity, solely on the basis of an individual's disability, from:

- Considering a qualified individual ineligible to receive an anatomical gift or organ transplant;
- Denying medical and other services related to organ transplantation;
- Refusing to refer the individual to a transplant center or a related specialist for the purpose of evaluation or receipt of an organ transplant;
- Refusing to place a qualified individual on an organ transplant waiting list; or
- Placing a qualified individual at a lower-priority position on an organ transplant waiting list than the position where the individual would be placed without the disability.

A covered entity could take an individual's disability into account when making treatment or coverage recommendations or decisions to the extent a physician, following an individualized evaluation, has found the disability to be medically significant to the provision of the anatomical gift. A covered entity could not consider the individual's inability to independently comply with post-transplantation medical requirements to be "medically significant" if the individual has the necessary support system to assist in complying with the requirements.

A covered entity would be required to make reasonable modifications in policies, practices, or procedures when necessary to allow an individual with a disability to access services, including transplantation-related counseling, information, coverage, or treatment, unless the entity can demonstrate the modifications would fundamentally alter the nature of the services. Similarly, a covered entity would be required to take necessary steps to ensure an individual with a disability is not denied services due to the absence of auxiliary aids and services, unless the entity can demonstrate taking the steps would fundamentally alter the nature of the services or would result in an undue burden.

An affected individual could bring an action in the appropriate district court for injunctive or other equitable relief if a covered entity violates the provisions of the bill, and the bill would require a district court in such an action to schedule a hearing as soon as possible and apply the same standards in rendering a judgment as would be applied in an action in federal court under the ADA.

The bill would state that none of its provisions shall be construed to require a covered entity to make a referral or recommendation for or perform a medically inappropriate organ transplant.

# Background

The bill was introduced by the House Committee on Federal and State Affairs at the request of Representative Davis. In the House Committee on Children and Seniors, conferees testifying in support of the bill included Representative Davis and a parent of a child with Down syndrome, another parent of a child with Down syndrome who also spoke on behalf of the Northwest Kansas Down Syndrome Society, as well as representatives of the Disability Rights Center of Kansas, Down Syndrome Guild of Greater Kansas City, National Alliance on Mental Illness Kansas, and National Down Syndrome Society. The Disability Rights Center of Kansas and the National Down Syndrome Society submitted additional written-only proponent testimony. Another parent of a child with Down syndrome, a family nurse practitioner, Children's Mercy Down Syndrome Clinic, and Kansans for Life also submitted written-only proponent testimony. No neutral or opponent testimony was provided.

According to the fiscal note prepared by the Division of the Budget, enactment of the bill would have no fiscal effect for the Kansas Department for Aging and Disability Services. The Board of Healing Arts indicates enactment of the bill could result in additional complaints regarding physicians, which would increase operational expenses if investigations were required, but a fiscal effect cannot be estimated. The Office of Judicial Administration indicates enactment of the bill could result in additional cases being filed, requiring additional personnel time to process cases, but a fiscal effect cannot be estimated. Any fiscal effect is not reflected in *The FY 2018 Governor's Budget Report*.