

## **HB 2343 Ensuring nondiscrimination of organ transplants on the basis of disability**

### **Committee on Children and Seniors February 15, 2017 Position: SUPPORT**

As the parent of a child with Down syndrome, I strongly support passage of HB 2343.

**Problem:** People with disabilities may face discrimination when seeking potentially lifesaving organ transplants. In such cases, discrimination often happens at the point where someone is referred for evaluation by a transplant center, before people are ever placed on the official transplant waiting list.

**Example:** In 2012, three-year-old Amelia Rivera of New Jersey went to the Children's Hospital of Philadelphia in critical need of a kidney transplant. Amelia's mother had offered her own kidney to save her daughter's life, and Amelia's treating specialists determined there was no medical reason not to approve the transplant. Nevertheless, Children's Hospital turned Amelia away because she had been diagnosed with Wolf-Hirschhorn syndrome, a genetic condition that causes intellectual disability. Fortunately, in the wake of tremendous public outcry, the hospital reversed its decision. Amelia received a successful kidney transplant in July 2013, and was afterward reported as "thriving and growing."

**Solution:** HB 2343 will:

**Clarify** that doctors, hospitals, transplant centers, and other health care providers are prohibited from denying access to necessary organ transplants solely on the basis of a qualified individual's disability;

**Require** that health providers consider, in evaluating the likelihood of a transplant's success, the full range of supports available to help a person with a disability manage their post-operative care;

**Include** a fast-track procedure for challenging discrimination to ensure that people in urgent need of an organ transplant can obtain timely resolutions to their claims.

Before being placed on a transplant registry, a treating or examining physician must refer an organ transplant candidate to a transplant center, and the center must approve them. Centers often have discriminatory policies regarding the candidates they will accept, and studies suggest that treating physicians discriminate in making appropriate referrals.

- A 2008 survey of 88 transplant centers conducted by researchers at Stanford University found that 85% of pediatric transplant centers consider intellectual or developmental disability as a factor in their determinations of transplant eligibility at least some of the time.<sup>1</sup> Fully 71% of heart programs surveyed "always" or "usually" considered ID/DD diagnoses when deciding eligibility for transplantation.
- Many potential transplant recipients never get as far as evaluation by a transplant center. The 2004 National Work Group on Disability and Transplantation survey reports that only 52% of people with I/DD requesting referral to a specialist for evaluation receive such a referral, and approximately a third of those for whom referral is provided are never evaluated.<sup>2</sup>

The proposed legislation would clarify doctors' obligations to avoid discrimination and to take into account available supports and services when deciding whether a patient can manage post-operative care. Doctors would still be able to consider a person's ability to follow post-operative care instructions, but would be required take into account supports (such as family help or professional caregivers) that the person can use to help them follow the treatment plan.

The legislation would also create an expedited process for resolving disputes so that people in medical crisis do not languish in the court system.

California, Maryland, Massachusetts and New Jersey have already passed laws banning organ transplant discrimination, and similar legislation has also been introduced in Delaware and Pennsylvania. All these bills were introduced in response to specific crises. Kansas should not wait for a catastrophic emergency to protect its citizens and families with disabilities from blatant discrimination, when the remedy could come too late. I strongly support passage of HB 2343 so that those with disabilities are treated fairly. While I hope that my son, Conner, who is 11 and has Down syndrome, never needs a lifesaving organ transplant, it will be great comfort knowing that we live in such a forward thinking state where those with disabilities are treated equally and fairly.

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<sup>1</sup>Richards CT, Crawley La Vera M, Magnus D (2009). *Use of neurodevelopmental delay in pediatric solid organ transplant listing decisions: Inconsistencies in standards across major pediatric transplant centers.* Pediatric Transplantation 13:843–850.

<sup>2</sup>The National Working Group on Disability and Transplantation (2004). *Summary Report of Individual and Family Disability Survey.*