



EQUALITY ♦ LAW ♦ JUSTICE

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**Testimony in Support of HB 2343
House Children and Seniors Committee
February 16, 2017**

Chairman Alford and members of the Committee:

My name is Rocky Nichols. I am the Executive Director of the Disability Rights Center of Kansas (DRC). DRC is a public interest legal advocacy organization that is part of a national network of federally mandated organizations empowered to advocate for Kansans with disabilities. DRC is the officially designated protection and advocacy system in Kansas. DRC is a private, 501(c)(3) nonprofit corporation, organizationally independent of state government and whose sole interest is the protection of the legal rights of Kansans with disabilities.

In Summary:

- HB 2343 will better ensure that doctors, hospitals, and health care providers cannot prevent access to medically necessary organ transplants simply because someone happens to have a disability. Disability is normal. It is not to be feared, or pitied, and certainly not used as a reason to deny someone a much needed organ transplant. Disability is a normal part of the human condition, and this bill helps reinforce that fact;
- HB 2343 will ensure that health providers must consider the full range of services and supports available to help a person with a disability manage their post-operative care;
- HB 2343 includes a “fast-track” process for a person with a disability to challenge discrimination in organ transplants, better ensuring they can receive justice in an expedited timeframe.

In short, this bill will prevent discrimination for life-saving and sustaining organ transplants based on disability.

This discrimination is real.

A 2008 survey of 88 transplant centers conducted by researchers at Stanford University found that:

- 85% of pediatric transplant centers consider neurodevelopmental status (which includes intellectual and developmental disabilities – I/DD) as a factor in their determinations of transplant eligibility;
- 46% of heart programs indicated that even mild or moderate cognitive impairment would be a relative *contraindication* to eligibility for a transplant;
 - *Contraindication is generally defined as “a reason to withhold a certain medical treatment due to the harm that it would cause the patient.”*
 - *It is inhumane and the height of demagoguery to think someone’s disability would be used as a reason to withhold medical treatment. Obviously, there is no “harm” to the person with a disability if they receive an organ transplant. The only harm is if they don’t receive the transplant.*
- 71% of heart programs surveyed always or usually utilized neurodevelopmental status in determinations of eligibility for transplantation;
- Upwards of 33% of kidney and liver programs utilized such factors.
- The International Society for Heart and Lung Transplantation’s heart transplantation criteria specifically states that intellectual or developmental disability or dementia “may be regarded as a relative contraindication to transplantation.”

A key problem is that 62% of all transplant programs said that informal processes guide their use of disability as a decision-making factor. The law must be very specific in spelling out protections regarding non-discrimination in organ transplants.

Unfortunately, potential transplant recipients with disabilities never get a referral to obtain a transplant. 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 a referral for a transplant, and approximately a third of those for whom referral is provided are never actually evaluated.

Frankly, there is no medical justification for denying organ transplants based on someone’s disability. According to a 2006 review of the available research literature in *Pediatric Transplantation*, this is no credible scientific data to even

support idea that a person's disability would constitute a heightened risk of worse outcomes post transplantation.

As one example, according to the Autistic Self Advocacy Network, "there are over fifty published cases of kidney transplants for people with intellectual disabilities. Success and medical adherence rates are comparable to that of the general population." This position is also supported in a 2010 review contained in the American Journal of Transplantation, which states "Currently, there is no scientific evidence or compelling data suggesting that patients with MR [intellectual disability] should not have access to organ transplantation."

Although the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act prevent discrimination based on disability, a policy paper and research from the Autistic Self Advocacy Network finds that "it has historically been difficult to enforce federal civil rights law within the area of medical decision-making. Due to the lack of medical knowledge on the part of the average patient or family member, people with I/DD often face little recourse when denied transplantation or even referral for consideration for such a procedure."

Also, most families are not able to effectively enforce their rights under the ADA because they must go through a long process of filing a lawsuit in federal court. This process can take years, cost thousands of dollars, and in the meantime people may die from their underlying medical conditions.

Finally, other State Legislatures have passed similar laws to protect their constituents with disabilities from this discrimination.

Thank you for your time and attention to this important bill, Mr. Chairman. I would stand for questions at the appropriate time.