



January 11, 2018

Committee on Public Health and Welfare

Regarding HB 2343 Ensuring nondiscrimination of organ transplants on the basis of disability

Dear Chairperson, Sen. Vicki Schmidt, and Committee Members,

Advocacy In Motion (AIM), a non-profit organization serving individuals with intellectual and developmental disabilities (IDD) in the greater Kansas City area, strongly supports the passage of HB 2343 Organ Transplant Nondiscriminatory legislation. We serve over 300 individuals with IDD and their families in Johnson County, Kansas. We provide services across the life-span with focus on employment training and supports for competitive, integrated employment at a prevailing wage or higher.

We commend the six states that have already passed similar legislation: California, New Jersey, Maryland, Massachusetts, Oregon and Delaware. Advocacy In Motion hopes Kansas will be the next leader on that list and advocates for the passage of this bill. We must recognize that people with IDD routinely face discrimination in healthcare; from consultations to referrals, determination of eligibility and placement on waiting lists. Often times, the discrimination is based upon assumptions that people with IDD have a lower quality of life than non-disabled people, and that people without disabilities may be more "deserving" of the organ. Additionally, it is often assumed that people with IDD are not able to comprehend directions or adhere to post-transplant treatment despite the support of highly-qualified caregivers through home and community based services (HCBS) and family members. Rather, it should be assumed that a person with IDD would have better post-transplant treatment support compared to non-disabled people.

We strongly agree with the findings in the legislation: "(5) state residents in need of organ transplants are entitled to assurances that they will not encounter discrimination on the basis of a disability. (b) A covered entity may not solely on the basis of an individual's disability: (5) place a qualified individual at a lower-priority position on an organ transplant waiting list than the position at which the qualified individual would have been placed if not for the disability. (2) If an individual has the necessary support system to assist the individual in complying with post-transplantation medical requirements, a covered entity may not consider the individual's inability to independently comply with the post-transplantation medical requirements to be medically significant for the purposes of paragraph (1) of this subsection."

Although ADA was passed over 17 years ago, leaders in the healthcare field and our community often perpetuate outdated stereotypes and preconceived notions about quality of life for individuals with IDD. As a special education teacher, professor with the University of Missouri – Kansas City School of Education, and Executive Director, it is a professional responsibility to know and teach others about

current information, and evidence-based, best practices when engaging with people with IDD. Our individuals with IDD have access to the best educational services, medical care, and community resources in history; and because of this, our individuals have more than doubled their lifespans in the past 30 years, and deserve proper consideration when an organ transplant may be beneficial.

This bill would go a long way to ensure that our community members with IDD would receive equal treatment, consideration and life-saving measures, just like our non-disabled community members. On behalf of the individuals and families we serve, Advocacy In Motion asks that you support the passage of HB 2343 and be nationally recognized as a state legislature that values ALL lives equally.

Respectfully,

A handwritten signature in black ink that reads "Sarah Wren Otto". The signature is written in a cursive style with a large initial 'S' and a distinct 'O' at the end.

Sarah Wren Otto
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