Written Testimony to the Ohio House of Representatives Health Committee

From Marc J. Tassé, PhD
The Ohio State University Nisonger Center
October 9, 2017

RE: House Bill 332:	Regards anatomical gifts, transplants, and discrimination
Sponsor:	Representative Niraj J. Antani
Co-sponsors:	Representatives Leland, West, Ingram, Kent, Keller, Lipps, Zeltwanger, Vitale, Romunchuk, Reidel, Becker

Chair Huffman, Vice-Chair Gavarone, Ranking Member Antonio, and Members of the Health Committee, thank you for allowing me to provide sponsor testimony on House Bill 332, which would ensure that individuals with disabilities will not be banned from an organ transplant waitlist solely based on their disability.

We appreciate the opportunity to provide testimony to the Ohio House of Representatives Health Committee regarding House Bill 332, which is before the 132nd General Assembly. I am the director of The Ohio State University Nisonger Center, a University Center for Excellence in Developmental Disabilities (UCEDD). The Nisonger Center was one of the first UCEDDs authorized under Public Law 106-402 (the Developmental Disabilities Assistance and Bill of Rights Act) and funded by the U.S. Administration on Intellectual and Developmental Disabilities. The national network of UCEDDs works toward a shared vision that foresees as nation in which all Americans, including Americans with disabilities, participate fully in their communities.

The Nisonger Center works to improve the health and access to health care for people with developmental disabilities. House Bill 332 modifies the revised code (sections 2108.36, 2108.37, and 2108.38) to prevent discrimination against Ohioans with disabilities in regards transplantation-related treatment and services. The Nisonger Center supports promoting health equity for people with disabilities.

Ellie was born with a severe heart defect and suffered heart failure at 15 days old. Although a heart transplant was likely her only chance for survival, doctors explained to her family that she was not eligible for the organ transplant waitlist in Ohio. Ellie has Down syndrome. Her family did not give up on their daughter and found a cardio-thoracic surgeon at Boston Children's Hospital who performed a heart transplant. Ellie is now a sassy, spunky, thriving preschooler.

Individuals with intellectual disabilities are being rejected for organ transplants frequently enough that *"their rights are a rapidly emerging ethical issue in this corner of medicine*," Lenny Bernstein writes for the *Washington Post's* Health and Science section March 4, 2017. In addition to medical issues, the 815 transplant teams in the United States review several other factors that could influence the transplant's success, including alcohol use, tobacco use, family support, ability to pay medical bills, and the patient's likelihood of being able to adhere to post-operative care regimen. However, aside from regulations in the Americans with Disabilities Act, transplant teams have autonomy to decide how to account for disabilities when making a determination.

As a result, some transplant teams consider co-occurring conditions heavily while others do not, Bernstein reports. For instance, a 2008 survey of 88 pediatric heart, kidney, and liver transplant

programs carried out by Stanford University found that 85% of pediatric transplant programs factor in disabilities when deciding who will be put on transplant waiting list. In an ongoing study, researchers are assessing adult and pediatric transplant programs and they've already found significant differences in eligibility decisions based on genetic disorders, such as Down syndrome, and intellectual disability. The researchers wrote, "*It does appear that the programs use this psychosocial criterion to distinguish among candidates, although consensus does not exist within the field to guide its usage."* Despite the potential for bias, available data show people with intellectual disability generally do as well as patients without disabilities after transplant surgery. However, a study published by OSU colleagues (Martens, Jones, & Reiss, 2006)[1] reported that the three-year survival rate for people with ID was 90%, the same as the nationwide overall survival rate for kidney transplant recipients.

The apparent bias against patients with disabilities in health care may stem from the widespread erroneous assumption that quality of life is severely compromised by disability. When asked to imagine their life after acquiring a paralyzing injury, health care providers estimated their life would be barely worth living. In fact only 18% of emergency care providers including emergency nurses, technicians, residents, and attending physicians imagined they would be glad to be alive after sustaining a spinal cord injury. This is in stark contrast to the 92% of spinal cord injury survivors who reported having a good quality of life. This misconception directly impacts patient care by limiting the type, scope, and aggressiveness of treatment options considered, including organ transplant. One study found that 71% of Residents in Pediatric Medicine questioned the aggressive treatment of children with severe disabilities.

Efforts are underway to change this discriminative practice. In October, 2016, 30 members of Congress in a letter to the HHS Office for Civil Rights asked for the office to issue instructions stating that discrimination in organ transplantation violates the ADA. The lawmakers also want the agency to specify that transplant teams should account for the support system in individuals with disabilities has when assessing whether the individual will be able to follow a postoperative care regimen- a factor that many transplant teams currently take into consideration when evaluating a potential patient. In a statement, an HHS spokesperson said the agency is working to "*clarify the obligations of covered entities participating in the transplant process and to provide equal access to their programs to individuals with disabilities*." Lawmakers in four states have approved legislation banning discrimination in transplant decisions.

Strong support such as yours will help ensure that Ohioans with disabilities receive high quality health care. Thank you for this opportunity to provide testimony on this important issue.

Respectfully,

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[1] Martens, M. A., Jones, L., & Reiss, S. (2006). Organ transplantation, organ donation, and mental retardation. *Pediatric Transplantation, 10*, 658–664.