

**Written Testimony to the Ohio Senate Health, Human Services, and Medicaid Committee**

**From Kara B. Ayers, PhD**

**University of Cincinnati Center for Excellence in Developmental Disabilities (UCCEEDD)**

**May 15, 2018**

**RE: Interested Party Testimony for HB 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 Burke, Vice Chair Beagle, Ranking Member Tavares and Members of the Senate Health, Human Services and Medicaid Committee:

My name is Dr. Kara Ayers. I am the Associate Director of the University of Cincinnati Center for Excellence in Developmental Disabilities. I am also a woman with a disability and the mother of three children, one of whom has developmental disabilities. The issue of discrimination in decisions related to organ transplantation is one of many issues in the realm of ethics and disability that leaves many people questioning, "Does that happen?" As Representative Antani and other constituents have shared, discrimination based on disability has and does happen related to organ transplantation. A 2009 study<sup>1</sup> found that 85% of pediatric transplant centers consider neurodevelopmental status as a key factor to determine eligibility. Some centers refuse to evaluate patients beyond this single factor. All forms of discrimination are cruel and unjust but this form is particularly deadly. Furthermore, decisions based on disability-status alone fail to recognize the data that suggests individuals with disabilities are just as-if not slightly more-likely to adhere to treatment compliance guidelines and follow-up.

Several studies, including a study led by Ohio State University researcher Marilee Martens<sup>2</sup>, have explored the outcome of organ transplantation in individuals with developmental and intellectual disabilities. One study found that survival rates were 100% at one-year and 90% at three-year follow-up intervals. Because individuals with disabilities often have the consistent support of family members and caregivers, they are often in good compliance with post-transplant medications and follow-up appointments. It has previously been argued that decreased intellectual functioning would mean that a person could not or would not comply with doctor's instructions following a transplant. This is not supported by research.

HB 332 would not reduce the power or authority of doctors to make sound ethical decisions on who should receive an organ. I'm aware that the supply and demand of life-giving organs is unfortunately far from equal. This bill, however, would reduce inequality and injustice in the decision-making process by removing the option to deny an organ on the basis of disability alone. Ethics committees and doctors should consider the best practices they use for every other patient without a disability. They consider the likelihood of a long survival rate. For many disabilities, including Down Syndrome, average length of life has increased with improved treatment outcomes. Doctors also consider variables like quality of life. While our lives, as people with disabilities, may look differently than yours, they are just as rich in value and complexity. Research also supports my anecdotal conclusion.<sup>3</sup>

I look to a future in which I hope it is no longer necessary to gather in support of new legislation to explicitly prohibit discrimination based on disability. The Americans with Disabilities Act already provides these protections but they are weakly enforced and leave room for interpretation in cases like these. The Convention on the Rights for Persons with Disabilities, unfortunately not ratified by the United States but ratified by 174 other nations, directly addresses discrimination on the basis of disability in organ transplantation. Let's join other states and other nations to prohibit this cruel and life-threatening form of discrimination on the basis of disability.

Thank-you for the opportunity to provide this written testimony. As always, the University of Cincinnati Center for Excellence in Developmental Disabilities (UCCEDD) is eager to serve as a resource for you as you make key legislative decisions for our state. We can connect research to relevant issues and get you in touch (privately or publicly) with constituents from the disability community directly impacted by issues and policy decisions. I appreciate your time and consideration.

Sincerely,



Kara B. Ayers, PhD

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#### Works Cited

<sup>1</sup>Richards, C.T., 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> Martens, M., Jones, L., & Reiss, S. (2006). Organ transplantation, organ donation, and mental retardation. *Pediatric Transplantation*. DOI: 10.1111/j.1399-3046.2006.00545.x

<sup>3</sup>Panocchia, N., Bossola, M., & Vivanti, G. (2010). Transplantation and Mental Retardation: What is the Meaning of Discrimination? *American Journal of Transplantation*, 10(4), 727-730, 729.