

# Public Health Committee JOINT FAVORABLE REPORT

**Bill No.:** SB-330  
AN ACT PROHIBITING DISCRIMINATION AGAINST PERSONS WITH A  
**Title:** DISABILITY WHO ARE CANDIDATES TO RECEIVE AN ANATOMICAL GIFT.  
**Vote Date:** 3/16/2022  
**Vote Action:** Joint Favorable Substitute  
**PH Date:** 3/14/2022  
**File No.:** 2494

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## **SPONSORS OF BILL:**

The Public Health Committee

## **REASONS FOR BILL:**

To ensure that individuals with disabilities can receive equitable medical care, this bill prohibits the eligibility to receive an organ from a living donor to be based on physical, mental, or intellectual disabilities. An exception can be made if a physician determines that a person's disability suggests that a transplant would not likely be accepted and if a person's disability would prevent them from meeting post-transplant medical requirements. An individual cannot be found ineligible so long as they have the necessary support to meet specific requirements.

## **RESPONSE FROM ADMINISTRATION/AGENCY:**

### **Peter Mason, Deputy Commissioner, Department of Developmental Services (DDS):**

DDS is in support of this bill, which moves towards equal treatment for persons with disabilities, and helps challenge assumptions made in the medical field about a person's worth or capacity. Because organs and tissue available for transplant are in short supply, recipients are chosen based on who will benefit the most. This is determined by several factors, including age, overall health, and even vaccination status. The notions that a person will not be healthy enough for transplant, or will not benefit because of their disability, should not affect the decision-making process.

### **Jeff Currey, State Representative:**

Rep. Currey, who submitted testimony alongside Rep. Ron Napoli, expressed surprise that transplant anti-discrimination legislation was not already in place. They were concerned that the original language only applied to organs and tissue donated after the donor's death. The substitute language specifies that this bill applies to donations from living donors as well.

**Rob Sampson, State Senator:**

After being alerted to this problem by constituents whose child has Down Syndrome and may at some point need a transplant, Sen. Sampson has proposed similar bills over the past few years. He believes this bill is a step in the right direction to protect vulnerable communities. Sen. Sampson noted related bills from other states that might serve as useful references for the final language. (Georgia HB 842 – 2019, and Wisconsin SB 538 – 2021).

**NATURE AND SOURCES OF SUPPORT:**

**Kathleen Flaherty, Executive Director, Ct Legal Rights Project, Inc.:**

Too often, our medical system devalues the lives of people with disabilities and cause some doctors to make treatment recommendations based on their belief that someone who is disabled may not be a life “worth living”. This bill would remove such a practice and instead assess whether the disabled person has supports in place to help them after a transplant. Medical decisions should not be made based on assumptions of what a person with a disability can or cannot do.

**Vignesh Subramanian, DS-Ambassador, National Down Syndrome Society (NDSS):**

NDSS is in support of this bill, which would ultimately codify the right of persons with disabilities to seek organ transplants. However, they suggest amending the language to explicitly prohibit other forms of discrimination against persons with disabilities in the transplantation process. The suggested language would include rejecting the following practices: refusing to place, or listing as a low priority, a disabled person for an organ transplant waiting list; refusing to provide referrals regarding medical and other services related to transplantation; and being denied insurance coverage for any procedure related to having received a transplant or related services.

**Beth Gard, President, Board of Directors, Down Syndrome Association of CT:**

Quality of life is not a judgment that medical professionals should make when determining the treatment of individuals with disabilities. She refers to the example of her 9-year-old son, who has Down Syndrome, and yet is no less physically active, intelligent, or happy than her two other children. Given the strides that we have made over the past few decades towards equality for those with disabilities, we should recognize the cruelty of allowing discrimination based on intellectual disability in such a serious matter as eligibility for a transplant.

**Lisa Paolillo, Chief Legal Officer, New England Donor Services (NEDS):**

While NEDS supports the bill, Ms. Paolillo requests that the language be removed from Connecticut's Uniform Anatomical Gift Act (UAGA). This is because the UAGA, most recently revised in 2010, was intended to bring Connecticut into alignment with the rest of the country on procedures for organ and tissue donation. This uniformity is crucial, because consistent legal standards facilitate speedy decisions, a necessity for donation. Transplant recipient matters are not addressed in the UAGA and adding this language to the act would compromise its uniformity. They suggest that it be more appropriately placed in Chapter 368II.

**Additional Sources of Support**

- Jesse Hubbard, Waterbury

**NATURE AND SOURCES OF OPPOSITION:**

No sources of opposition were provided for this bill.

**Reported by: Dallas Emerle**

**Date: 4/4/2022**