



STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
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The Honorable John Carney
Governor

John McNeal
SCPD Director

MEMORANDUM

DATE: February 21, 2017

TO: All Members of the Delaware State Senate
and House of Representatives

FROM: Ms. Jamie Wolfe, Chairperson
State Council for Persons with Disabilities

RE: H.B. 21 (Organ Transplant Discrimination)

The State Council for Persons with Disabilities (SCPD) has reviewed H.B. 21.

Background is contained in the attached January 5 press release. It recites that there were 471 Delawareans awaiting organ transplants on December 30, 2016. There is nationwide concern over disability-based discrimination in qualifying and receiving an organ transplant. Consistent with the attached articles, New Jersey enacted a ban in 2013 on discrimination in the organ transplant system based on a mental or physical disability with no significant relationship to the transplant. The July 18, 2013 article described the problem as follows:

Individuals with mental or physical disabilities sometimes face discrimination in organ transplant scenarios because of assumptions regarding their quality of life or their ability to comply with complex post-transplant medical requirements, regardless of whether the individual has an effective support system in place to ensure compliance.

H.B. No. 21 would disallow a "covered entity" from engaging in discrimination in the organ transplant system. Discrimination would include refusal to refer an individual to a transplant center, refusal to place an individual on a waiting list, or placing the individual at a lower priority position on a waiting list (lines 66-77). H.A. No. 1 was placed with the bill on January 19. It would authorize judicial enforcement by the Attorney General or an aggrieved person. Remedies would include a civil penalty and the availability of damages.

The SCPD is giving a general endorsement of the bill.

Thank you for your consideration and please contact SCPD if you have any questions regarding our position or observations on the proposed legislation.

cc: The Honorable Matthew Denn, Attorney General
Mr. Brian Hartman, Esq.
Governor's Advisory Council for Exceptional Citizens
Developmental Disabilities Council

HB 21 organ transplant discrimination 2-21-17



Delaware House of Representatives
Rep. Debra Heffernan

For Immediate Release:
January 5, 2017

Contact: Jen Rini
Work: (302) 744-4399

Heffernan bill bans organ transplant discrimination

Measure helps ensure Delawareans with disabilities are not denied life-saving healthcare

DOVER – Delawareans with mental or physical disabilities would not be denied organ transplants on the sole basis of a disability under proposed legislation from Rep. Debra Heffernan, D-Brandywine Hundred.

Transplant centers consider a variety of medical and psychosocial criteria when evaluating organ transplant candidates.

But people with disabilities have reported discrimination early on in the process, which has prevented them from being placed on the official transplant waiting list. A [2008 survey](#) out of Stanford University found that 85 percent of the 88 transplant centers surveyed considered neurodevelopmental status as a factor in determining transplant eligibility at least some of the time.

Take Amelia Rivera, a toddler from New Jersey with an intellectual disability and rare genetic disorder. Amelia's family was told by a children's hospital that the child was not eligible for a kidney transplant as a result of her disability, according to a policy brief from the Autistic Self Advocacy Network.

House Bill XX would attack such discrimination and protect Delawareans with disabilities so they would not be deprived of transplant services or referrals, nor would they be barred from an organ transplant waiting list.

"All Delawareans have a right to health care. People should not be denied life-saving organ transplants on the basis of a disability," Heffernan said. "There is the misconception that people with disabilities are unable to manage post-operative treatment plans and therefore are less likely to benefit from a transplant. That's just not true. People with disabilities can live healthy, long lives after organ transplants with help from family and other support systems."

Rep. Melanie George Smith, D-Bear, and Senate Majority Whip Nicole Poore, D- New Castle, have signed on as co-sponsors of the measure.

Similar legislation has passed in New Jersey and California. Pennsylvania and Massachusetts are working through measures, as well.

According to the United Network for Organ Sharing, 471 Delawareans were waiting for organ transplants as of Dec. 30, 2016. Nationwide, 119,168 people are in need of a life-saving organ transplant and, on average, 22 people die daily while waiting.

HB xx has been assigned to the House Health and Human Development Committee. The General Assembly returns to session on January 10.

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Christie signs bill banning hospitals and doctors from denying disabled people organ transplants



By Susan K. Livio | NJ Advance Media for NJ.com

[Email the author](#) | [Follow on Twitter](#)

on July 18, 2013 at 1:18 PM, updated July 18, 2013 at 6:46 PM

TRENTON — Hospitals and doctors would be prohibited from taking a patient's mental or physical disability into account when being considered for an organ transplant under a bill Gov. Chris Christie signed into law today.

The legislation stemmed from the experience of Amelia Rivera, 5, of Stratford, who was diagnosed with a developmental disability known as Wolf-Hirschhorn syndrome and needed a kidney transplant. But in January 2012, a doctor at the Children's Hospital of Philadelphia informed Amelia's parents that she was not a candidate for a transplant because of her disability.

The hospital later apologized, and emphasized that it did not have a policy of disqualifying people with disabilities as potential transplant candidates.

According to a recent blog post by Amelia's mother, Chrissy, both mother and child are undergoing tests to prepare the young girl to receive her mother's kidney.

"People with developmental disabilities should not be treated as second-class citizens," said Senate President Stephen Sweeney (D-Gloucester), one of the bill's sponsors. "Their disabilities do not make them any less human or worthy of respect and common decency. They should be afforded the same rights as anyone would want when entering a hospital."

The bill, (S1456), permits a mental or physical disability to be taken into account by a physician or surgeon to the extent that disability may have a medical effect on the transplant's success, but an outright denial because of a disability alone is illegal. People may go to court to seek a judge's help in enforcing the law, if necessary.

"It is incomprehensible that a doctor or surgeon would just rule someone out for a transplant based solely on their physical or mental capacity," said Sen. Joseph Vitale, (D-Middlesex), also a sponsor. This legislation will fix that, without the government interfering in important decisions that have to be made by doctors and patients and their families."

RELATED COVERAGE

- [Bill to prevent discrimination against disabled people in need of transplants gets panel approval](#)
- [Sweeney wants to prevent hospitals from denying organ transplants to the disabled](#)

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MORE

By Dennis Thompson
HealthDay Reporter



(HEALTHDAY)

WEDNESDAY, Jan. 25, 2017 (HealthDay News) – Pressure is mounting for the U.S. organ donation network to tackle one of the thorniest ethical questions it's ever faced – whether a person with intellectual disabilities should be denied access to a transplant.

A bipartisan group of 30 legislators from the U.S. Congress petitioned the Department of Health and Human Services in October to "Issue guidance on organ transplant discrimination with regards to persons with disabilities," according to a new opinion piece in the Jan. 26 *New England Journal of Medicine*.

The legislators' request follows several highly publicized cases in which people with intellectual disabilities have either fought to receive a transplant or have been outright denied a place on a waiting list, said co-author Dr. Scott Halpern. He's an associate professor of medical ethics and health policy at the University of Pennsylvania's Perelman School of Medicine.

Around 120,000 people are waiting for a donated organ that's needed to save their lives, and every 10 minutes another person is added to the list, the U.S. Department of Health and Human Services says.

Every day, 22 people on the waiting list die without receiving a new organ, according to federal statistics.

Because of the constant shortage, the nation's system of organ banks – the Organ Procurement and Transplantation Network, managed by the United Network for Organ Sharing (UNOS) – has to be stringent about who is given a place on the waiting list, Halpern said.

"It's very well established that transplant centers can and should deprioritize patients whose own conditions or social supports make them less likely to promote the viability of the organ by adhering to complicated medical regimens following transplantation," he said.

"That would constitute a waste of an organ that would not allow it to benefit the person to whom it was allocated and would deprive someone else who could have benefited," Halpern explained.

In recent years, transplant centers have struggled with whether an intellectual difficulty should prevent a person from receiving a donated organ, the authors noted.

A 3-year-old New Jersey girl named Amelia Rivera made headlines in 2012 when she was denied a kidney transplant because she has Wolf-Hirschhorn syndrome, a genetic disorder that caused severe intellectual impairment, the authors said. Following an online campaign that drew more than 50,000 people to her cause, she received the transplant.

That same year, a 23-year-old Pennsylvania man with autism named Paul Corby was permanently denied a heart transplant. His hospital group, Penn Medicine, denied the operation "given his psychiatric issues, autism, the complexity of the process, multiple procedures and the unknown and unpredictable effect of steroids on his behavior," according to a letter from the hospital.

The debate revolves around two main questions, Halpern said.

~~First, the decision to transplant an organ into a patient with intellectual disabilities will often mean that another patient with no such impairment will die for lack of a transplant.~~ Halpern doesn't think much of that argument, however.

"Clinicians ought not to be making decisions about the quality of lives of patients," he said. "Those are value judgments that patients and family members have the authority to make."

Noted medical ethicist Arthur Caplan agreed. "I think we need to be generous in terms of where we draw the line," said Caplan, founding head of the NYU Langone Medical Center's Division of Bioethics in New York City.

A trickier question involves whether intellectually disabled people can care for themselves properly following the transplant, so their donated organ isn't wasted.

Transplant recipients must participate in postoperative recovery programs and take complicated regimens of immune-suppressing drugs to keep their bodies from rejecting the new organ, Halpern said.

"There are reasonable concerns that patients with cognitive impairment may be among those for whom adherence to medical regimens would be suboptimal, but there is a real paucity of data to support those concerns," Halpern said.

National studies have shown that children with intellectual disabilities fare just as well as other kids following a transplant, but those children have parents or caregivers on hand to make sure they stick to their treatment, the authors said.

There have been no solid studies of transplant outcomes among adults with mild Intellectual disability, for whom concerns about adherence to treatment would be better founded, the article stated.

Halpern said UNOS needs to beef up the available evidence by requiring that more data be reported on transplant patients with intellectual disabilities.

He also called for the establishment of regional review boards to examine the evidence on "edge cases" and provide guidance to transplant centers.

"That's not to say the review board should have the authority to tell a transplant center what to do," Halpern said. "The virtue of an independent regional review board would be to provide some objective guidance for transplant centers to consider in a listing decision."

Caplan disagreed with the idea of a review board, arguing instead for the creation of clear lines that would define who is and isn't eligible for a transplant.

"I'm not very excited about handing this off for a new kind of committee," Caplan said. "I think this is going to have to be a policy issue for UNOS and they're not going to be able to punt it over to another committee."

UNOS declined to comment on the article.

Existing federal anti-discrimination laws likely will "push toward inclusion in a way this piece doesn't cover," Caplan predicted. "I think the law and Congress are both pointing in that direction."

"Hopefully the editorial will prod movement," Caplan concluded. "It's just been kicked around with a lot of saber-rattling in terms of lawsuits and finger-pointing. Patients and their families deserve clear guidance."

More information

For more on organ donation and transplants, visit the [U.S. Department of Health and Human Services \(https://www.organdonor.gov/about/facts-terms/donation-faqs.html\)](https://www.organdonor.gov/about/facts-terms/donation-faqs.html).

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