

Organ Transplant Disability Bias Gets Second Look Under Trump

By Shira Stein

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- Head of HHS Office of Civil Rights said stopping discrimination based on disability is priority
- Organization overseeing organ transplants examining ethics of transplant list criteria

The first time Paul Corby got an organ transplant evaluation, his mother Karen Corby could tell the doctor had already decided not to put him on the donor wait list.

Paul is autistic and carries a Princess Peach doll for comfort, and the doctor asked why he was carrying the doll, she said. When the doctor asked Paul to name the 19 medications he was already taking, he couldn't.

When Karen asked for a written copy of the doctor's decision denying Paul a recommendation for a heart transplant, she saw the reason in black ink—it was his autism.

Disability rights activists have been working since the mid-1990s to stop doctors from denying organ transplants to people with intellectual and developmental disabilities. Their efforts could finally be paying off.

The director of the Department of Health and Human Services Office for Civil Rights wants to stop this behavior. He and his staff are discussing a written guidance warning transplant centers that such discrimination is illegal. Separately, the nonprofit organization that facilitates organ transplants, the Organ Procurement and Transplantation Network (OPTN), is looking at the ethical implications of determining organ transplant recipients based on disability.

Both the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 prohibit health-care providers from denying patients access to services and programs based on disability. But neither law explicitly says it's illegal to refuse to make someone transplant eligible.

'Serious Attention' From HHS

OCR Director Roger Severino said in an interview the issue "merits serious attention," and his agency considers it a priority to stop this kind of discrimination.

"We're looking to see what other appropriate clarifications would be in order," Severino told Bloomberg Law.

Discrimination against people with disabilities based on stereotypes is “prohibited under federal law and we intend to enforce that vigorously,” he added.

Still Happening

Eight states have passed laws making the practice illegal, but advocates want the OCR to issue a similar statement that would apply to all states.

A 2008 survey found that 85 percent of pediatric transplant centers sometimes consider neurodevelopmental disability when determining transplant eligibility. A 2006 literature review found that there is little data to support the idea that intellectual or developmental disabilities would constitute a higher risk of poorer outcomes after organ transplantation.

Congress has also encouraged the OCR to issue guidance. The House Appropriations Committee in 2017 expressed concern “about reports of continued discrimination against persons with disabilities in organ transplant.”

Initial Progress

The OCR resolved a complaint in February against the University of North Carolina Health Care system after a doctor allegedly denied a patient a place on the organ transplant list based on a disability. UNC didn't pay any financial penalties, but it made the patient eligible for a transplant.

Severino said he doesn't want to see similar incidents.

The UNC resolution is the “first sign of progress on this issue in a long time,” Ari Ne'eman, a consultant on disability policy with the ACLU and former president of the Autistic Self Advocacy Network, said.

Disability rights issues tend to be more bipartisan than other health issues, which means it can be easier for government enforcers to act, Susan Mizner, director of the disability rights program at the ACLU, said.

For that reason, filing a complaint with the OCR is a good option for people who are denied placement on the organ transplant list. “It's very easy for complaints to take a lot of time to get resolved in large federal bureaucracies, but this was a relatively quick resolution,” she said, referring to the UNC complaint.

The North Carolina case is instructive for how discrimination plays out, Ne'eman said. Sometimes doctors or transplant centers will say explicitly they won't perform a transplant because of a disability. More often, the reasoning will be that people with disabilities can't manage their post-operative treatment needs.

Previous Promises

Advocates got a verbal promise in 2013 from then-OCR Director Leon Rodriguez to issue guidance on the issue, according to an advocate. But it didn't happen.

Rodriguez said the OCR wanted to pursue a guidance on organ transplant discrimination, but other things got in the way. It would have required a tremendous amount of internal advocacy. "We just didn't do it," he said.

Then, as now, it's a big undertaking. Rodriguez said coordination with the Health Resources and Services Administration, which deals with organ transplant services, is paramount "in order to accomplish a meaningful, actionable guidance in this area."

Severino said he's up to the challenge. "All of HHS is on board with making sure persons with disabilities aren't discriminated against when it comes to life-saving care," he said, adding that this problem has received significant support from Republicans and Democrats.

Unethical Criteria

Separately, the ethics committee for the organ transplant nonprofit OPTN is considering whether it's ethical to consider intellectual disabilities in transplant evaluations, Keren Ladin, vice chair of committee, said. The committee wants to discuss a draft at its public meeting in early April and put it out for public comments in August.

The paper wouldn't mandate any policy changes. Those would come from other policymaking committees at OPTN or the government.

The OPTN is also considering surveying transplant centers about their practices in these situations, United Network for Organ Sharing spokeswoman Anne Paschke said.

The ADA is intentionally broad to apply across different policy areas. Because of this, some people argue that the law doesn't apply to organ transplantation, Rebecca Cokley, director of the disability justice initiative at the left-leaning Center for American Progress, said in an interview.

Now, some advocates worry that changing the ADA to specifically mention organ transplants could open the door to saying ADA doesn't apply to everything, Cokley said. That could lead to more discrimination.

Giving Up

Even before Karen Corby found out her son needed a new heart, doctors in the emergency room blamed his chest pain on autism, she said. "As soon as they knew he was different, they said it was anxiety."

Two weeks after that emergency room visit, Paul was in cardiac intensive care.

Karen thought about filing a lawsuit against the hospital for not putting Paul on a transplant list, but she couldn't find a lawyer to represent her. She contacted the Justice Department, and an attorney said there are no regulations governing who can receive an organ, so there's no basis for a lawsuit.

Karen and Paul have been dealing with his heart problems for over 10 years. He's stable now, and they've decided not to get him evaluated again. Paul told her that he would rather die than go through all those tests to be told no again.

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