



Pass "Paul's Law," HB 585, to Protect People with Disabilities Against Organ Transplant Discrimination

In 2012, three-year-old Amelia Rivera of New Jersey went to the Children's Hospital of Philadelphia in critical need of a kidney transplant. Amelia's mother had offered her own kidney to save her daughter's life, and Amelia's treating specialists determined there was no medical reason not to approve the transplant. Nevertheless, Children's Hospital turned Amelia away because she had been diagnosed with Wolf-Hirschhorn syndrome, a genetic condition that causes intellectual disability. Fortunately, in the wake of tremendous public outcry, the hospital reversed its decision. Amelia received a successful kidney transplant in July 2013, and was afterward reported as "thriving and growing."

But people with disabilities in Pennsylvania still face widespread discrimination when seeking potentially lifesaving organ transplants. Much of this discrimination happens at the point where someone is referred for evaluation by a transplant center, before people are ever placed on the official transplant waiting list.

Paul Corby, an autistic young man in need of a heart transplant, is still fighting for a chance at a heart transplant. Although he meets all the medical criteria for transplant, doctors at the University of Pennsylvania Transplant Center have turned him away due to his disability.

Paul's Law would supplement existing disability non-discrimination laws in order to:

- Clarify that doctors, hospitals, transplant centers, and other health care providers are prohibited from denying access to necessary organ transplants solely on the basis of a qualified individual's disability;
- Require that health providers consider, in evaluating the likelihood of a transplant's success, the full range of supports available to help a person with a disability manage their post-operative care;
- Fast-track organ transplant discrimination complaints to ensure that people in urgent need of an organ transplant can obtain timely resolutions to their claims.

Background on Organ Transplant Procedures

Before being placed on a transplant registry, a treating or examining physician must refer an organ transplant candidate to a transplant center, and the center must approve them. Centers often have discriminatory policies regarding the candidates they will accept, and studies suggest that treating physicians discriminate in making appropriate referrals.

- For one example, policies at the University of Pennsylvania Transplant Center include "Active and unstable psychiatric illness" as an absolute contraindication for renal transplants and impose similar

bars on heart and lung transplants for people with mental illness, regardless of supports that may be available to help the patient comply with post-operative care.

- A 2008 survey of 88 transplant centers conducted by researchers at Stanford University found that 85% of pediatric transplant centers consider intellectual or developmental disability as a factor in their determinations of transplant eligibility at least some of the time.¹ Fully 71% of heart programs surveyed “always” or “usually” considered ID/DD diagnoses when deciding eligibility for transplantation.
- Many potential transplant recipients never get as far as evaluation by a transplant center. The 2004 National Work Group on Disability and Transplantation survey reports that only 52% of people with I/DD requesting referral to a specialist for evaluation receive such a referral, and approximately a third of those for whom referral is provided are never evaluated.²

Although the Americans with Disabilities Act outlaws discrimination on the basis of disability, including discrimination by doctors, many health providers fail to recognize that this can apply to discriminatory denials of organ transplants.

- They may also not understand their obligation to make reasonable modifications, such as to a policy approving people for transplant only if they can manage post-operative care independently and without support.
- Many families can't effectively enforce their rights under the Americans with Disabilities Act because they must go through a long process of filing a lawsuit in federal court. This process can take years, cost thousands of dollars, and in the meantime people may die from their underlying medical conditions.

The proposed legislation would clarify doctors' obligations to avoid discrimination and to take into account available supports and services when deciding whether a patient can manage post-operative care. Doctors would still be able to consider a person's ability to follow post-operative care instructions, but would be required take into account supports (such as family help or professional caregivers) that the person can use to help them follow the treatment plan.

The legislation would also create an expedited process for resolving disputes so that people in medical crisis do not languish in the court system.

California and New Jersey have already passed laws banning organ transplant discrimination, and Maryland is expected to pass similar legislation soon. All these bills were introduced in response to specific crises. Pennsylvania should not wait for a catastrophic emergency to protect its citizens and families with disabilities from blatant discrimination, when the remedy could come too late.

¹ Richards CT, 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.

² The National Working Group on Disability and Transplantation (2004). *Summary Report of Individual and Family Disability Survey*.