

SB155, known as “Lila’s Law”: Organ Transplant Anti-Discrimination Bill

Why this bill is needed:

- The most common reason individuals with a disability are denied an organ transplant is the misconception that people with disabilities – especially those with intellectual or developmental disabilities – are unable to manage complicated post-op treatment plans.
- Providers may also incorrectly assume that individuals with disabilities have a lower quality of life than people without disabilities and they would not benefit as much from life-saving transplants.

What this bill does:

- Prohibits the following based on an individual’s mental or physical disability alone:
 - Deeming them ineligible for a transplant
 - Denying any services related to the transplant
 - Refusing to refer them to a transplant center for evaluation
 - Refusing to place them on a waiting list
 - Placing them at a lower priority on waiting list
 - Declining insurance coverage for the procedure
- Requires “reasonable modifications” (transplantation-related counseling, information, coverage, and treatment) for the qualified patient unless the covered entity can demonstrate that making the modifications would fundamentally alter the nature of services or result in undue burden.
- Allows a qualified individual’s disability to be taken into account when making treatment or coverage recommendations once doctors conduct an individual evaluation and find the disability to be medically significant to the provision of the transplant.
- Ensures a qualified individual’s inability to independently comply with post-op care cannot be taken into account if the individual has the necessary support system to help them comply with post-op care.
- Provides a speedy legal path for individuals who allege a violation.

What it doesn’t do:

- Require referral, recommendation, or performance of a medically inappropriate organ transplant. Individuals with a disability must still meet essential eligibility requirements for a transplant.

Other states who have passed similar legislation:

- California, New Jersey, Maryland, Massachusetts, Oregon, Delaware, Kansas, Ohio, Pennsylvania, Washington, Louisiana, Indiana, Virginia, Iowa, Missouri, Florida.