

LEGISLATURE

New Arizona law prohibits organ transplant discrimination based on disability

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Arizona transplant awareness and organ donor specialty license plate. Arizona Department of Transportation

A new Arizona law prohibits health care providers from discriminating against people with disabilities in organ transplant decisions, which advocates and studies say is common.

House Bill 2659 passed unanimously through the state Legislature and Gov. Doug Ducey signed it into law on March 25. The law says health care providers may not refuse a patient an organ transplant or put them lower on the organ transplant waiting list solely on the basis of disability unless the provider deems their disability “medically significant” to the transplant.

The law allows a patient with a disability who believes they have been discriminated against to sue in state court to stop the discrimination. The law requires courts to prioritize such cases on their dockets.

The federal Americans with Disabilities Act already prohibits health care providers from discriminating against people with disabilities. However, the ADA does not specifically mention organ transplant decisions. That causes some health care providers to fail to recognize that the ADA applies to such situations, said Cathi Herrod, president of the conservative Center for Arizona Policy, which supported HB 2659.

The Arizona law will clarify to providers that they are prohibited from discriminating in organ transplant decisions based on disability, Herrod wrote in an email to The Arizona Republic.

The Center for Arizona Policy was one of three major Arizona organizations that supported the law. The others were the Arizona Center for Disability Law and the William E. Morris Institute for Justice at Arizona State University. No individuals or organizations opposed the bill.



Rep. Steve Kaiser, R-Phoenix, looks on during debate of HB 2898, a K-12 education bill, during the House Appropriations Committee hearing at the Arizona Capitol in Phoenix on May 25, 2021. David Wallace/The Republic

The bill's sponsor, Rep. Steve Kaiser, R-Phoenix, did not respond to requests for comment.

“Despite existing civil rights protections, individuals with Down syndrome and other disabilities continue to face both willful and unintended discrimination in organ transplantation, which threatens their ability to access health care when they need it most,” Herrod wrote. “HB 2659 aims to correct this injustice.”

At least 30 states have passed similar laws, according to the National Down Syndrome Society.

Studies show it is common for people with neurodevelopmental disabilities like Down syndrome or autism to be denied organ transplants.

A 2008 Stanford study found that 43% of pediatric organ transplant centers said they “always” or “usually” consider a child’s neurodevelopmental disability when deciding whether to place them on the transplant list. In 2020, researchers at Stanford and Baylor published a study finding that, out of more than 200 adult transplant programs surveyed, 30% said they would not give a transplant to an adult with an IQ under 35, which is considered a severe intellectual disability.

Transplant centers in Arizona say they already don’t discriminate based on disability. David Lozano, spokesperson for Banner Health, which has organ transplant centers in Phoenix and Tucson, said Banner Health doesn't deny transplants based on disability. Jim McVeigh, spokesperson for Mayo Clinic, which runs a hospital with an organ transplant center in Phoenix, said the new law wouldn’t change Mayo Clinic’s practices.



The scene outside the emergency room at Banner Desert Medical Center in Mesa on June 9, 2020. David Wallace/The Republic

However, Scottsdale resident Josie White says discriminatory practices are happening in organ transplant decisions in Arizona.

White testified before the Arizona House and Senate Health and Human Services committees that when her daughter Riley was four months old, she underwent three open heart surgeries in a span of 26 days in an effort to save her life from a congenital heart defect. Riley's family assumed that, should her heart continue to fail, she would be eligible for a heart transplant. But White said they later learned this was not the case, solely because Riley has Down syndrome.

Today, Riley is nine-and-a-half years old. She studies in a general education third grade classroom, swims on a swim team and loves gymnastics. White described having to travel to Massachusetts to get Riley care at a hospital that has told her family it would give Riley a heart transplant if she needs one.

“We continue to receive our cardiac care three thousand miles away,” White said, “knowing they will give our girl every chance at life and not withhold a life-saving heart transplant based on her intellectual disability.”

[According to a 2019 report by the National Council on Disability](#), one reason people with disabilities are often denied transplants is because health care providers believe they won't be able to follow post-operative care requirements because of their disability.

Jon Meyers, the executive director of the Arizona Developmental Disabilities Planning Council, said this notion is “much more myth than fact,” as people with intellectual or developmental disabilities almost universally have caregivers who would be able to help them with such requirements.

The new law says a person's inability to independently comply with post-operative care requirements may not be considered medically significant if the person has a support system in place to help them with the requirements.

The National Council on Disability report found that a disability unrelated to the reason for a transplant will generally have little to no impact on the likelihood of the transplant being successful. The report also found that, if a person with a disability receives adequate support, their disability should have a very limited impact on their ability to adhere to a posttransplant care regime.

Still, the report found that disability-based discrimination in organ transplant decisions continues to take place, even in states with laws on the books prohibiting it. The report says that “the informal manner in which organ transplant eligibility decisions are often made makes it difficult to determine whether discrimination occurred,” as patients may not be aware that the reason they were denied was because of their disability.

Herrod said such discrimination often occurs because health care providers misunderstand the law. The new Arizona law will help prevent that by clarifying to providers that prohibitions on discrimination against people with disabilities apply to organ transplant decisions, she said.

“We expect Arizonans with disabilities will no longer face discrimination when needing an organ transplant,” Herrod said in an email, “and health care providers will have clarity and guidance about how to account for and accommodate disability in their practice.”