

Organ transplants for people with disabilities: **Know Your Rights!**

The process of obtaining an organ transplant is incredibly complex. Finding the right specialist, getting an evaluation from a hospital transplant team, making it onto an organ transplant waiting list, and preparing for an upcoming transplant surgery can be difficult to manage at the same time as coping with a serious illness.

People with disabilities who need organ transplants face another potential hurdle: the risk that a doctor, hospital, or transplant organization will refuse access to an organ transplant on the basis of the patient's disability. This discriminatory treatment may be motivated by the perception that people with disabilities are more difficult patients, that people with disabilities cannot comply with complicated post-transplant medication regimens, or that saving the lives of people with disabilities is simply not a good use of scarce organs that could be used to help nondisabled people.

Fortunately, people with disabilities are protected against discrimination by federal and state laws. Hospitals and doctors also may be governed by ethical boards or committees that prohibit discrimination against people with disabilities.

If you or someone you love has a disability and is in need of an organ transplant, it is important to know your rights when dealing with doctors, hospitals, transplant organizations, or other people whose assistance you need in order to obtain a potentially lifesaving transplant.

Federal and State Laws Governing Organ Transplantation

To obtain an organ transplant, you or your loved one may need approval or assistance from many different health care professionals, including:

- Your primary care doctor
- Specialists who provide treatment for the condition that gives rise to your need for an organ transplant
- Doctors who treat you for other medical conditions that may influence your organ transplant
- The transplant center at the hospital where you are seeking the transplant

- The transplant team at the transplant center
- Your insurance carrier
- Local, regional, and national organ and tissue banks and procurement networks
- The United Network of Organ Sharing, which operates the Organ Procurement and Transplantation Network and operates the national transplantation information database.

Although most or all of these entities are covered by some law that prohibits disability-based discrimination, each may be covered by a different law.

The Americans with Disabilities Act

The Americans with Disabilities Act (ADA) prohibits public accommodations and state-run programs from discriminating against people with disabilities. This includes:

- Doctors' offices, including primary care doctors and specialists
- State-run hospitals and transplant centers within those hospitals
- State-run health coverage providers, including Medicaid

The Rehabilitation Act

In addition, the Rehabilitation Act prohibits federally-funded programs, including Medicaid, and Medicaid providers, from discriminating against people with disabilities. This includes:

- The United Network of Organ Sharing
- Doctors who accept reimbursement through Medicaid or Medicare
- Hospitals and transplant centers that receive federal funding, including Medicaid and Medicare.
- Health plans that receive federal funding, including Medicaid, Medicare, and private health plans funded through the Medicaid program

The Affordable Care Act

The Affordable Care Act, among other things, prohibits most health plans from discriminating against people with disabilities. Insurance plans covered by the Affordable Care Act include health plans purchased on the new health insurance marketplaces and, beginning in 2015, many plans provided through employers.

State Anti-Discrimination Laws

Many states have their own laws that prohibit disability-based discrimination by doctors, hospitals, and health insurance providers.

In addition, New Jersey and California have passed laws that specifically prohibit organ transplantation discrimination against people with disabilities. These anti-discrimination laws cover most of the professionals and organizations that may be involved in organ transplantation decisions, including doctors, hospitals, and organ banks.

What Kind of Actions Count as Discrimination?

When dealing with professionals and organizations that are covered by the Americans with Disabilities Act, Rehabilitation Act, or state laws prohibiting disability-based discrimination in organ transplants, you are entitled to be free from discrimination and to receive reasonable accommodations or modifications to policies and procedures. In particular:

Health care providers, including doctors, hospitals, and transplant registries, cannot refuse to provide services – such as performing an organ transplant surgery, making a referral to a transplant center, or placing a person on the waiting list – for discriminatory reasons. These reasons might include the belief that people with disabilities have a lower “quality of life” and that it is better that organs be used to save the lives of people without disabilities.

Health care providers may refuse to provide services if they have a good reason to believe the transplant might not succeed or might not improve the patient’s health, but there must be evidence backing this belief.

Health care providers must make reasonable modifications in policies, practices, and procedures and must provide auxiliary aids and services. For example, a doctor may be required to allow patients to wait in a quiet place

instead of an overcrowded waiting room, to communicate through typing or picture boards, or to bring a service dog to some areas of the doctor’s office. The doctor must also provide additional “auxiliary aids and services” that are necessary to ensure full communication about a patient’s medical care, such as providing a sign-language interpreter, visual diagrams, or concrete written instructions.

Health care providers may be required to consider supports that a person with a disability may use when deciding if a patient can manage their post-transplant care. Before performing a transplant, the transplant team considers whether a patient will keep up with the complicated post-transplant treatment plan, including taking all prescribed medications on time.

The Americans with Disabilities Act and the Rehabilitation Act require that the transplant team make reasonable modifications of this policy for people with disabilities. Reasonable modifications might include considering whether family members, friends, or community-based support providers can help the patient follow the post-transplant treatment plan. New Jersey and California have passed laws that explicitly require doctors to consider supports that can help patients with post-operative treatment. Even in other states, the Americans with Disabilities Act and Rehabilitation Act may require doctors to consider supports that can help with post-operative treatment.

Federally and state-funded health coverage providers, and health insurance plans covered by the Affordable Care Act, may not refuse to cover procedures that are covered for people without disabilities. Coverage providers may deny coverage if they have a good reason to believe the transplant might not succeed or might not improve the patient’s health, but there must be evidence backing this belief.

What Do I Do if I Experience Discrimination?

According to a 2004 survey, only 52% of people with intellectual or developmental disability who asked to be referred to an organ transplant specialist received a referral. Of those who did receive a referral, a third never received an evaluation. If you or your loved one has been turned down for a transplant for reasons that you think are discriminatory, there are steps you can take to protect your or your loved one’s rights.

Keep Careful Records.

Make sure to keep careful records of your communications with health care providers. In particular,

- Ask that doctors put important decisions – such as their reasons for a decision not to transplant – in writing. Otherwise, keep careful notes of what is said during face-to-face or telephone conversations.
- Request a copy of your medical record. In order to obtain medical records for a loved one who is an adult, your loved one may need to sign a form giving you permission to receive these records.
- Keep copies of all written communications, including letters and emails.

Seek a Second Opinion.

Different doctors and transplant centers may make different decisions about whether you or your loved one is a candidate for a transplant. To the extent that you can, feel free to visit other specialists and transplant centers to find one that is willing to recommend a transplant. You may wish to seek out transplant centers in states that explicitly prohibit disability-based discrimination in organ transplantation decisions, such as New Jersey or California.

Your regular doctor or developmental specialist may be helpful. For example, if a transplant center refuses to place you or your loved one on a waiting list due to concerns about ability to follow post-transplant treatment recommendations, it can help to ask your doctor to write a letter explaining why these concerns are unfounded.

If possible, videotape yourself or your loved one on a “good day” and offer to share the video with clinicians and transplant evaluation teams. This videotape may help to humanize you or your loved one to doctors who believe that people with significant disabilities lack sufficient “quality of life” to benefit from transplant, and may help challenge diagnosis-based assumptions that you or your loved one lack the ability to comply with post-transplant care.

Seek Review by the Hospital Ethics Board.

Most hospitals have ethics boards that are responsible for ensuring that the hospital and its doctors do not discriminate against people with disabilities. If you believe that a hospital or hospital transplant team has discriminated against you or your loved one, you may ask the ethics committee to review your case. Different hospitals may

follow different procedures for ethics board review, but in general it is best to:

- Write a short, clear letter describing the hospital’s decision
- To the extent that you can, include documents showing that you or your loved one would benefit from a transplant and could comply with post-transplant care (with or without support). For example, you may want to include a letter from your regular doctor or specialist showing that a disability will not interfere with the success of a transplant, or a letter from a support provider willing to help with post-transplant care.

File an Administrative Complaint.

The U.S. Department of Health and Human Services and the Department of Justice both have complaint processes through which consumers can report violations of the Americans with Disabilities Act and Rehabilitation Act. The appropriate agency to hear your complaint depends on which type of service provider is committing discrimination. Some providers may be under the jurisdiction of both agencies. If you submit your complaint to one of these two agencies, it may refer your complaint to the other one if it feels that the other agency would be better qualified to address your complaint.

While you do not need an attorney to file an administrative complaint, you are encouraged to seek an attorney’s advice prior to filing if one is available to you. See below for advice on finding an attorney.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

The Department of Health and Human Services reviews complaints about discrimination by:

- Health care providers that receive payments from Medicaid or Medicare, including doctors, hospitals, or other programs, even if you (or your loved one) are not one of their patients covered by Medicaid or Medicare;
- Other providers that receive funding through the Department of Health and Human Services, including the United Network for Organ Sharing, which is responsible for maintaining the nationwide organ waiting list;
- Any other health program that was established under the Affordable Care Act or receives federal funding, including the statewide health insurance exchanges; and

- Programs funded by the State or local government, including state hospitals.

The form for filing a complaint with the Department of Health and Human Services is available online at <http://www.hhs.gov/ocr/civilrights/complaints/index.html>. If you wish to file a complaint, you must do so within 180 days after experiencing discrimination.

DEPARTMENT OF JUSTICE

The Department of Justice reviews complaints about discrimination by:

- Programs funded by the State or local government, including state hospitals state programs, including state-funded hospitals; and
- Places of public accommodation, including hospitals, doctor's offices, nursing or rehabilitation facilities, and pharmacies.

Many of these providers will also be under the jurisdiction of the Department of Health and Human Services, either because they are state or local programs or because they receive Medicare or Medicaid payments. In those circumstances, you may file a complaint with either agency.

For instructions on filing a complaint with the Department of Justice, see http://www.ada.gov/filing_complaint.htm. The deadline for filing a complaint might vary by state. As a result, if you wish to file a complaint, you should do so promptly, or consult an attorney about the appropriate deadline.

File a Civil Lawsuit.

The Americans with Disabilities Act, the Rehabilitation Act, the nondiscrimination sections of the Affordable Care Act, and many state laws prohibiting discrimination, all permit those who have suffered disability discrimination to file a lawsuit challenging the discrimination. Depending on the circumstances, you may be entitled either to compensation for harm you suffered, or to a court order against continued acts of discrimination against you. You may file a lawsuit even if you have already filed an administrative complaint with the Department of Health and Human Services or the Department of Justice.

The New Jersey law prohibiting organ transplantation discrimination provides an expedited, or fast-tracked process for challenging denials of organ transplants. This process may be particularly helpful in situations where there is an urgent need for a transplant.

You are strongly encouraged to seek representation by an attorney before filing a lawsuit. For more information on finding an attorney, see below.

Finding Legal Assistance

A good attorney can be a significant help at any point when challenging suspected discrimination, and is particularly important if you plan on filing a lawsuit against a health care provider. In order to avoid missing deadlines for filing complaints or lawsuits, you should see an attorney as early as possible. Finding an attorney to represent you can be difficult, however, especially if you cannot afford to pay for one out of pocket.

Each state has one or more Protection and Advocacy organization dedicated to helping people with disabilities access services and avoid discrimination. Although they may not be able to represent you directly, they are often a good place to start when seeking legal help. To find your local Protection and Advocacy organization, see <http://www.ndrn.org/en/ndrn-member-agencies.html>.

Bar Associations in each state also operate attorney referral services. Some state bar associations charge a fee for these services. To access the directory in your state, see <http://apps.americanbar.org/legalservices/lris/directory/>. Please keep in mind that some attorneys who list "disability" as a practice area actually focus on disability benefits claims, not discrimination. Attorneys who list their practice as "civil rights" often can assist with discrimination claims, including disability discrimination claims.

Other useful sites for finding legal assistance include:

- Disability Rights Education and Defense Fund (DREDF), www.dredf.org
- American Civil Liberties Union Local Affiliates, <https://www.aclu.org/affiliates>
- FindLaw, www.lawyers.findlaw.com
- Nolo, www.nolo.com/lawyers