

Organ transplants for people with disabilities: A Guide for Advocates

Introduction

Since organ transplantation first became available as a treatment option, people with disabilities have faced significant barriers to accessing this life-saving procedure. Perhaps the most common barrier is the misconception that people with disabilities — especially those with intellectual, developmental, or psychiatric disabilities — are unable to manage complicated post-operative treatment plans and that, as a result, people with disabilities are less likely to benefit from the transplant. Providers may also incorrectly assume that people with disabilities have a lower quality of life than people without disabilities and would not benefit as much from life-saving transplants as nondisabled people, or that they are unable to give informed consent to transplantation.

People with disabilities can, with support, successfully manage post-operative treatment and stay healthy for many years after transplantation surgery. These supports may include help from family members and friends, community-based services and supports funded by Medicaid, school-based supports, and other community-based options. In addition, legal experts and leading bioethicists have concluded that, when transplantation is likely to significantly improve the health of a person with a disability, denying transplantation on the basis of that person's supposed lower quality of life or inability to consent would amount to illegal and unjustified discrimination.

This Guide for Advocates provides advice for advocates interested in preventing disability-based discrimination in organ transplantation. This guide offers information that advocates can use in a variety of channels, from reaching out to individual doctors or hospitals to advocating for laws that prohibit disability-based discrimination in organ transplantation. By taking action, advocates can help dispel myths about people with disabilities who need organ transplants and promote policies that protect the right to lifesaving care.

Lief's Story

Lief is a 10-year-old autistic child who relies on typing and other alternative methods to communicate. At the age of nine, Lief was diagnosed with dilated cardiomyopathy, a potentially fatal condition for which he would ultimately need a heart transplant. Two transplant centers refused even to evaluate Lief for a transplant as a result of his disability. Nevertheless, Lief's family was able to locate a program willing to perform the transplant, and Lief was placed on the organ transplant waiting list.

While on the waiting list, Lief became the first known autistic person to receive an implanted Left Ventricular Assistive Device (LVAD), which helped his heart pump blood until a compatible organ donor could be found. Although Lief needed this device in order to survive until a suitable match was found, doctors at the hospital where Lief was initially hospitalized had assumed that Lief would not be able to tolerate the discomfort associated with the device. Nevertheless, Lief was able to live with the LVAD for several months until a suitable donor heart was located.

Seven months after his initial hospitalization, Lief underwent successful heart transplantation surgery. Six months later, Lief is healthy, is managing post-operative treatment well with help from his family, and shows no signs of transplant rejection.

As Lief's success with the LVAD and heart transplant illustrates, people with disabilities may show resilience and ability to comply with complex regimens that defies clinicians' prior assumptions. As Lief's mother noted, "until a person is faced with death we have no idea what they will do to save their own lives. He developed new strengths and abilities in order to fight for his life and it worked."

Without timely access to heart transplantation, Lief would not be alive today. Yet his history of rejection by transplant programs suggests that many children and adults with similar disabilities — particularly

those who lack the ability to “shop” through many different transplant programs — might never be able to access life-saving transplants. According to a 2008 survey of 88 transplant centers, 85% of pediatric transplant centers consider neurodevelopmental status as a factor in their determinations of transplant eligibility at least some of the time, with heart transplant centers being more restrictive in their decisions than kidney or liver programs.¹ Moreover, some transplant centers may refuse even to evaluate people with developmental disabilities as candidates for transplant. As was the case with the transplant centers that refused to evaluate Lief, these refusals may be communicated over telephone to the patient’s treating physicians and not documented as determinations of ineligibility. This lack of transparency may make it difficult for patients and their families to detect and challenge discrimination.

1. Richards, C.T., 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.

Ensuring Nondiscriminatory Access to Organ Transplantation: What Can Advocates Do?

Know the Facts

The first step to advocacy – whether it is for yourself, your family member, or for others – is learning the facts. In order to be effective, you may need to be familiar with existing laws against discrimination, research on organ transplants for people with disabilities, and resources available to help people with disabilities manage post-transplant care.

Existing Laws Against Discrimination: the Americans with Disabilities Act, Rehabilitation Act, and State Laws

The Americans with Disabilities Act (ADA) and the Rehabilitation Act prohibit disability-based discrimination by doctors’ offices, state-run hospitals, and organizations that receive federal funding. Organizations that receive federal funding may include organizations funded through contracts with the federal government such as the United Network for Organ Sharing (UNOS), as well as hospitals and doctors who see Medicaid and Medicare patients.

People and organizations covered by the ADA and Rehabilitation Act must not discriminate against people with disabilities. Discrimination may include refusing to provide health care to someone who needs it because that person has a disability. It also may include refusing to make a “reasonable modification” to policies or procedures that are necessary in order to ensure that a person with a disability can access health care.

New Jersey and California have passed laws specifically prohibiting disability-based discrimination in organ transplantation decisions, and similar legislation is pending in Pennsylvania. The ADA and Rehabilitation Act prohibit disability discrimination even in states that have not have laws specifically banning disability-based organ transplantation discrimination.

For more information about laws protecting people with disabilities from organ transplant discrimination, please see the companion publication to this Guide, “Organ transplants for people with disabilities: Know Your Rights!”

Medical Research: People with Disabilities Can Successfully Receive Organ Transplants

Recent studies confirm that, provided they receive adequate support with post-operative care, people with developmental or intellectual disabilities have a comparable likelihood of transplant success to people without disabilities. The results of recent studies are summarized in Table 1 below. Although most published studies focus on kidney transplants, this is likely due to the fact that kidney transplantation is the most common form of organ transplant procedure.¹

1 Martens, M.A., Jones, L., & Reiss, S. (2006). Organ transplantation, organ donation, and mental retardation. *Pediatric Transplantation*, 10, 658–664 at 661.

Study	Population	Trans-plant Type	Findings
Martens, Jones, & Reiss (2006) ¹	Patients with Intellectual Disability	Kidney	Three-year survival rate for people with ID was 90%—the same as the nationwide overall survival rate for kidney transplant recipients.
Ohta et al. (2006) ²	Children with Intellectual Disability	Kidney (grafts)	For all of the 25 children studied, kidney grafts were still functioning 41 months after surgery.
Galante, Dib, & Medina-Pestana (2010) ³	Patients with Intellectual Disability	Kidney (grafts)	5-year graft survival rate for 16 patients with ID was identical to rate for matched patients without ID, and adherence to medical recommendations was 100%.
Samelson-Jones, Mancini, & Shapiro (2012) ⁴	Patients with Intellectual Disability or Brain Injury	Heart	Four of five patients surveyed were still alive up to 16 years after transplant. One in five (20%) had a poor outcome as a result of non-adherence to treatment, which is comparable to the average rate of non-adherence to post-transplant medications among nondisabled people (23%).

Table 1. Summary of Recent Research on Transplant Outcomes for People with Disabilities.

Managing Post-Operative Care

Ability to manage post-operative care is a frequently raised concern when people with significant disabilities seek organ transplants. People with disabilities may need lifelong assistance with the medication and related care regimens that are necessary to ensure that the transplant is a success. With the right supports, however, people with significant disabilities can lead long lives after transplant surgery. As a result, the American Society of Transplantation recommends that, when evaluating an individual with a cognitive disability as a potential candidate for transplant, “[c]areful evaluation of the support system available to the potential recipient is imperative.”

several months after his heart attack and was still healthy when researchers reviewed his case twelve years later. During the 12 years after the transplant, he had only one hospital admission and had no evidence of heart disease. He received support from his parents, with whom he lived until their deaths, and later from a 24-hour home attendant while living in his own apartment.²

2. Samelson-Jones, E., Mancini, D. M., & Shapiro, P. A. (2012). Cardiac Transplantation in Adult Patients with Mental Retardation: Do Outcomes Support Consensus Guidelines? *Psychosomatics*, 53(2), 133-138.

Case Study

Mr. C,¹ a 30-year-old man with dilated cardiomyopathy, experienced a heart attack that deprived his brain of oxygen, causing permanent disability. Although he had previously been able to live independently, after his heart attack he experienced severe short-term memory loss and had difficulty planning and making health decisions. He needed reminders to perform daily tasks such as bathing, and a psychiatric consultant described him as having cognitive abilities “akin to a preschool aged child.” Nevertheless, Mr. C received a successful heart transplant

Mr. C’s story shows that even people with significant support needs can live long, healthy lives after transplantation. Indeed, many people with disabilities already receive extensive and effective support managing their health care. Moreover, many candidates without disabilities, such as young children, also require, and receive, support with medication management.

The following resources can help children and adults with developmental disabilities manage their medical care:

Family and Support Networks

Children and adults with disabilities may rely on family, friends, or other unpaid supporters for assistance managing their health care.

1. The patient’s name has been omitted to protect his confidentiality.

Just as parents of nondisabled children may monitor their children's medication, parents of disabled children can help ensure their children follow post-operative care plans. Parents may rely on other informal supports, such as grandparents, friends, religious congregations, or community volunteers, to assist them in managing their child's care.

Adults with disabilities may rely on support networks as well, including their parents, friends, religious congregations, or community centers.

Medicaid-Funded Services

Many adults and children with intellectual and developmental disabilities qualify for home and community-based support services through Medicaid. These services can include:

- **PERSONAL ASSISTANCE** with managing medications, bathing, dressing, and maintaining a sanitary environment;
- **HOME HEALTH AIDES** who can assist in medication management, monitoring health status, and providing skilled care;
- **CASE MANAGEMENT**, including ensuring that clients schedule and attend routine doctor's appointments;
- **TEACHING SKILLS** for independent living, including health and medication management;
- **RESPITE CARE** for times when caregivers need time away from administering care; and
- **TRANSPORTATION** to doctor's offices and other health care providers' offices.

Even if a patient is not currently enrolled in Medicaid or receiving these services, he or she may qualify for these services after the transplant or, in the case of a child, after he or she reaches the age of adulthood. Children with disabilities may be eligible for Medicaid even if their parents are not. Some states also have "buy-in" programs that allow families to purchase Medicaid for children with disabilities, even if the family makes too much money to be eligible for traditional Medicaid.

School-Provided Services

All school-aged children under age 21, regardless of the extent of disability, are eligible to receive educational services under the Individuals with Disabilities Educa-

tion Act (IDEA). Children are eligible to attend school even if they are medically frail, require intensive assistance or supervision, or do not use language to communicate.

The IDEA requires that schools provide necessary related services, including administering medication, to children with disabilities during the time they spend at school. Schools may even be required to provide skilled nursing care to children who must receive such care during the course of the school day.² These services provide a much-needed respite during the day for family members or other care workers who are responsible for assisting the child outside school hours.

If medication management is likely to be a significant concern for the child after the child reaches adulthood, schools may be required to provide health care transition planning and lessons on medication and health maintenance as part of the child's Individualized Education Plan (IEP). This can help ensure that the child either has learned to manage his or her own medication, or has a medication support plan in place, before reaching adulthood.

Community Resources and Centers for Independent Living

If a disabled individual is not eligible for Medicaid- or school-funded community services, they nevertheless may be able to obtain health management supports either by utilizing local resources in their communities, paying out of pocket, or obtaining supports through long-term care insurance policies.

Centers for Independent Living (CILs) can be extremely helpful in locating potential local sources of support. CILs are community-based organizations that provide peer support, independent living skills training, and information and referrals for community-based supports. Adults with disabilities, as well as families of children with disabilities, may use CILs to provide training on health management skills or referrals to community organizations that can help manage post-operative transplant care. To find your local Center for Independent Living, see <http://www.ilru.org/html/publications/directory/index.html>.

State Protection and Advocacy organizations (P&As) may also provide assistance in securing access to supports, including Medicaid- and school-funded services. These

² Cedar Rapids Community School District v. Garret F., 526 U.S. 66 (1999).

organizations receive federal funding to help ensure that people with disabilities receive health care and other benefits to which they are entitled. To find your local P&A, see <http://www.ndrn.org/en/ndrn-member-agencies.html>.

Planning for the Future

When a person with a disability receives support primarily from parents or other family members, it may be reasonable to consider how that support will continue to be available. With responsible planning, however, people with disabilities may continue to receive support they need even after the people who now support them pass away or become unable to meet their needs. For example, people with disabilities may enroll in Medicaid waiver programs that provide community-based supports. Families may also set up special needs trusts or other financial plans to provide supports beyond those provided through Medicaid. Furthermore, the absence of a mechanism for ongoing appropriate support should not constitute a reason to deny a person with a disability access to transplantation, if they would be able to manage their post-operative care needs with appropriate support.

Quality of Life

There is increasing consensus among lawyers and bioethicists that health care providers should not deny treatment to people with disabilities based on the assumption that they have a lower “quality of life.” As early as 1992, the U.S. Department of Health and Human Services took the position that deeming people with disabilities to have a lower “quality of life,” and refusing health care on that basis, would violate the Americans with Disabilities Act.³

Considering “quality of life” in organ allocation decisions may result in unfair discrimination against individuals with disabilities. Clinicians’ estimates may, as a result of their own “horror of handicap,” dramatically undervalue the actual quality of life of disabled patients.⁴ In reality, people with significant developmental and intellectual disability – including those who need assistance with basic tasks, those with co-occurring physical disabilities, and those who do not communicate using language – may lead long, rich, and fulfilling lives in their communi-

ties. Moreover, patients with disabilities who received organ transplants may experience marked improvements in quality of life.⁵

Supporting Decisionmaking Regarding Organ Transplantation

Many individuals with intellectual, developmental, and psychiatric disabilities may experience challenges understanding and making decisions regarding organ transplantation. Nevertheless, the American Society of Transplantation has found that “[s]ome individuals with irreversible cognitive impairment, although unable to give informed consent, may nevertheless benefit from transplantation.”⁶

As noted above, the Americans with Disabilities Act and Section 504 of the Rehabilitation Act require reasonable modifications of policies, practices, and procedures when necessary to ensure that people with disabilities can access services on a nondiscriminatory basis. Like consideration of supports that may help people with disabilities manage post-operative care, participation in supported healthcare decisionmaking processes may be both a reasonable and necessary modification to standard practice in order to ensure access to transplantation to people who would benefit from it.

Educate Doctors and Hospitals about Best Practices

Advocates can make a difference at an individual and local level by educating doctors, hospitals, and even medical associations about how to avoid discrimination on the basis of disability. Advocates may set out simply to change the mind of a doctor and hospital in a particular case, or may go further by pushing doctors, hospitals, and medical associations to adopt formal nondiscrimination policies.

Advocating for formal policies and procedures is a particularly effective way of preventing future discrimination. When reaching out to a doctor’s office, hospital, transplant center, or medical organization, advocates should ask whether that organization has a formal policy governing organ transplantation for people with intellec-

³ Sullivan, L. (1992, January 9). Oregon Plan is Unfair to the Disabled [Letter to the Editor]. *New York Times*. Available online at <http://www.nytimes.com/1992/09/01/opinion/l-oregon-health-plan-is-unfair-to-the-disabled-659492.html>.

⁴ Field, M.A. (1993). Killing the Handicapped - Before and After Birth. *Harvard Women’s Law Journal*, 16, 79, at p. 88.

⁵ Ohta, T., Motoyama, O., Takahashi, K., Hattori, M., Shishido, S., Wada, N., et al. (2006). Kidney transplantation in pediatric recipients with mental retardation: clinical results of a multicenter experience in Japan. *Journal of Kidney Disease*, 47, 518–527.

⁶ Kasiske, B.L., Cangro, C.B., Hariharan, S., Hricik, D.E., Kerman, R.H., Roth, D., et al.: American Society of Transplantation. (2001). The evaluation of renal transplantation candidates: clinical practice guidelines. *American Journal of Transplantation*, 1, 3–95.

tual, developmental, or other disabilities. If the organization does have a policy, advocates should request a copy of the policy and, if necessary, ask for changes that will better protect against disability-based discrimination. If the organization does not have a policy, advocates can urge the organization to develop one.

By persuading doctors, hospitals, and other health care providers to adopt the following policies and practices, advocates can help ensure that organ transplant decisions are based on actual ability to benefit from transplantation and not on improper stereotypes, assumptions, or policies that unfairly exclude people with disabilities. Advocates may wish to refer clinicians to “Organ Transplantation for People with Disabilities: A Guide for Clinicians,” a companion to this Guide, which includes these policy recommendations.

Evaluating Patients with Disabilities for Organ Transplantation

- When evaluating a person’s likelihood of transplantation success, clinicians should consider not only the person’s independent ability to manage post-operative care but also the person’s ability to manage post-operative care with appropriate supports. In particular, clinicians should consider:
 1. all present and future supports available to the person,
 2. whether the person has a history of success at managing his or her treatment using existing supports, and
 3. whether additional supports available to the individual could improve the individual’s ability to manage his or her treatment.

A person’s previous difficulty managing health care should not automatically bar him or her from receiving an organ transplant. Clinicians should keep in mind that people with disabilities may be more motivated to adhere to a treatment regimen that is necessary in order to save their lives than they were to adhere to treatments for less severe health conditions, and that they may benefit from supports that were previously unavailable.

Evaluation of a person’s support system may even require looking past supports already in place in order to locate additional supports that

may be used to assist the potential transplant recipient manage his or her care. Support from multiple sources may help people follow their health care plans even when no single support would be adequate.

- Clinicians should not base transplant referral, acceptance, or listing decisions on the assumption that a disability will reduce the likelihood of transplant success, in the absence of
 1. evidence from peer-reviewed, controlled research, and/or
 2. the specific individual’s history of surgical outcomes.
- Concerns that an individual cannot give “informed consent” to transplantation should not be an absolute bar to transplantation. Instead, clinicians should work with the individual and his or her support network (e.g., designated health care proxy, health care support provider, or, where the individual is a minor, the individual’s parents or legal guardians) using the principles of supported decisionmaking in order to ensure that transplantation is consistent with the individual’s wishes.
- Clinicians should not base transplant referral, acceptance, or listing decisions on assumptions about the impact of disability on the individual’s quality of life after transplant.

Supported Decisionmaking: Respecting Patients’ Right to Make Organ Transplant Decisions

As noted earlier, it is important that doctors respect patients’ rights to make decisions about their own care. Although people with intellectual and developmental disabilities may need extra support in order to make an informed choice about their health care, doctors and hospitals should not reject people for organ transplantation solely on the basis of their perceived inability to make their own healthcare decisions. The following policies will help ensure that people with intellectual and developmental disabilities can access lifesaving organ transplants while respecting their right to reject unwanted treatment.

When the patient is a minor.

As in the case of other children, minors with disabilities are not legally capable of providing informed consent to major surgery. Nevertheless, as in the case of all children under consideration for transplantation, clinicians should ensure that children with disabilities agree to the transplant and, to the extent that is age-appropriate, ensure that they are actively involved in the transplant decision process.⁷ When children with disabilities experience communication barriers that make it difficult to explain procedures and/or ascertain the child's wishes, clinicians should work with families and/or individuals with expertise in augmentative and alternative communication (AAC) in order to maximize communication ability. However, lack of access to communication should not constitute a rationale for denying a child access to transplantation.

When the patient is an adult under legal guardianship.

Many adults with intellectual or developmental disabilities may have court-appointed guardians for the purpose of health care decisionmaking. Legal guardians for healthcare purposes are, like the legal guardians of minors, typically empowered to provide informed consent for procedures such as organ transplantation. As a result, guardianship status should not constitute a rationale for denying a person with a disability access to transplantation. Nevertheless, as with minors, clinicians should ensure, to the extent possible with communication methods available to them, that adults under guardianship both agree to the transplant and actively participate in the transplant decision process.⁸ Clinicians should work with guardians, family members, friends, and individuals with expertise in augmentative and alternative communication (AAC) in order to maximize communication ability.

When the patient is an adult not under legal guardianship.

Many adults with disabilities, despite significant needs for support with decisionmaking, may not have legal guardians. The growing trend within the disability community is to shift away from guardianship towards less

restrictive alternatives for decision-making support, such as supported decision-making. Clinicians should not assume that patients diagnosed with cognitive disabilities necessarily lack the ability to provide informed consent to transplantation surgery, nor should they assume that individuals who initially appear unable to provide informed consent need a legal guardian as a prerequisite to receiving care. Instead, when it appears that a patient lacks the ability to provide informed consent to transplantation, clinicians should investigate potential avenues to augment the patient's ability to understand his or her health care decisions, including:

- Permitting the patient to bring a trusted support person with him or her to appointments and interviews, to assist him or her in understanding health-related information (the patient may also wish to execute HIPAA authorizations to disclose health-related information to the support person or persons);
- Providing information in cognitively accessible formats to the fullest extent possible, such as through visual or video demonstrations;
- Working with the patient, family members, friends, and individuals trained in augmentative or alternative communication (AAC) in order to improve the patient's ability to understand information, ask questions, and communicate decisions; and
- Determining whether the patient has previously appointed an agent, representative, proxy, or surrogate to make or assist with health care decisions, or whether the patient has executed a valid advance directive making his or her wishes known.

Clinicians who continue to have concerns regarding a patient's ability to provide informed consent, even after supports have been provided, should consult with appropriate ethical and legal authorities such as the hospital ethics committee.

When evaluating the potential utility of an organ transplant for a person with a disability, clinicians should focus on "quality of health" instead of "quality of life."⁹ Quality of health may include factors such as increased life expectancy, improved organ function, and reduction

⁷ Kasiske, B.L., Cangro, C.B., Hariharan, S., Hricik, D.E., Kerman, R.H., Roth, D., et al.: American Society of Transplantation. (2001). The evaluation of renal transplantation candidates: clinical practice guidelines. *American Journal of Transplantation*, 1, 3–95.

⁸ Id.

⁹ Panocchia, N., Bossola, M., & Vivanti, G. (2010). Transplantation and Mental Retardation: What Is the Meaning of a Discrimination? *American Journal of Transplantation*, 10(4), 727–730, at p. 729.

in need for alternative interventions such as dialysis. Unlike quality of life, clinicians have both expertise and experience evaluating and predicting patients' quality of health.¹⁰

Advocate for Non-Discrimination Legislation in Your State

Although the Americans with Disabilities Act and Rehabilitation Act already prohibit a broad spectrum of disability-based discrimination throughout the United States, many doctors and hospitals continue to reject people with intellectual or developmental disabilities seeking organ transplants. This continued practice may stem, in part, from lack of awareness that denial of organ transplantation on the basis of disability may violate the ADA or Rehabilitation Act. People with disabilities and their families may also face difficulty enforcing their rights under the ADA or the Rehabilitation Act because the need for an organ transplant is often extremely urgent and the process to obtain relief under the ADA or Rehabilitation Act may take several years.

As a result, advocates in some states have lobbied for laws that specifically prohibit disability-based discrimination in organ transplantation. As a result of their efforts, New Jersey and California now have laws banning organ transplant discrimination, and similar legislation is pending in Pennsylvania.

Elements of an Effective Anti-Discrimination Law

Effective state laws against organ transplantation should:

- Prohibit doctors, hospitals, transplant centers, and other health care organizations from denying access to necessary organ transplants on the basis of disability;
- Require that doctors, hospitals, transplant centers, and other health care organizations, when evaluating the likelihood of successful transplant for a person with a disability, consider not only the person's ability to manage post-operative care independently but also the full range of supports available to help the person manage post-operative care;
- Include a "fast-track" procedure for challenging discrimination. This will help ensure that people

in urgent need of an organ transplant can obtain timely resolutions to their discrimination claims.

The Autistic Self Advocacy Network has drafted Model Organ Transplant Anti-Discrimination Legislation that includes these elements. State legislators may choose to introduce this model legislation as-is, or they may use it as a starting point for legislation that is specifically tailored to the needs of their state.

How to Advocate for Anti-Discrimination Legislation

Advocates can help promote anti-discrimination legislation in their states by:

- Writing to their state legislative representatives discussing the prevalence of organ transplantation discrimination, explaining the importance of ensuring that people with disabilities have access to lifesaving organ transplants, and asking them to introduce anti-discrimination legislation similar to the Model Organ Transplant Anti-Discrimination Legislation. A directory of state representatives is available at http://openstates.org/find_your_legislator/.
- Writing a Letter to the Editor of local newspapers, discussing the importance of ensuring people with disabilities have access to lifesaving organ transplants and expressing support for organ transplantation anti-discrimination legislation.
- Seeking out partners in advocacy, such as local disability affinity organizations, patients' rights groups, or faith-based advocacy coalitions. Advocates should let these groups know that organ transplantation discrimination is an important issue to them and ask them to help promote organ transplantation anti-discrimination legislation in their state.