

Organ transplants for people with disabilities: A Guide for Clinicians

Introduction

Since organ transplantation was introduced as a viable treatment option, people with disabilities have faced significant barriers to accessing the 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 comply with post-operative treatment regimens and that, as a result, people with disabilities have a lower likelihood of transplant success. In addition, providers may incorrectly assume that people with disabilities have a lower quality of life than people without disabilities and therefore would not benefit as much from life-saving transplants, or that they are unable to give informed consent to transplantation.

People with disabilities can, with adequate supports, successfully manage post-operative treatment and stay healthy for many years after transplantation surgery. These supports may include assistance from family members and friends, community-based services and supports funded by Medicaid, school-based supports, and other community-based options. In addition, both federal legal experts and leading bioethicists have concluded that, when transplantation is likely to provide significant health benefits, denying transplantation to people with disabilities on the basis of their supposed lower quality of life or inability to consent constitutes illegal and unjustified discrimination.

When evaluating an individual with a disability as a possible candidate for transplant, clinicians should be aware of existing research on transplantation outcomes for people with disabilities and of the range of supports available to assist with medical decision-making and postoperative care — whether or not the individual already has such supports in place. Clinicians should also be aware that people with disabilities, including those with significant intellectual, developmental, or psychiatric disabilities, may lead rich, fulfilling lives post-transplantation. Clinicians should not assume that people with disabilities are not good candidates for transplant solely as a result of intellectual, developmental, or psychiatric disability.

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 Transplantation

The Americans with Disabilities Act (ADA) and the Rehabilitation Act prohibit disability-based discrimination by doctors’ offices, state-run hospitals, and recipients of federal funding, including health providers that accept reimbursement through Medicaid or Medicare and organizations funded through contracts with the federal government such as the United Network for Organ Sharing (UNOS). Discrimination includes both refusal to provide services to qualified individuals with disabilities and refusal to make reasonable modifications in policies and practices that are necessary in order to ensure that people with disabilities may access services. In addition, New Jersey and California have passed legislation specifically prohibiting disability-based discrimination in organ transplantation decisions, and similar legislation is pending in Pennsylvania.

In order to avoid discrimination on the basis of disability, clinicians should ensure that they do not make decisions regarding referral for transplants, acceptance into transplant programs, or listing on organ transplant registries based on improper stereotypes or assumptions, and that they make reasonable allowances in their referral, ac-

ceptance, and listing practices to account for the specific needs of people with disabilities. In particular:

- When evaluating an individual’s likelihood of adherence to postoperative treatment, clinicians should consider
 1. all present and future supports available to the individual,
 2. whether the individual 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 patient’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.

- 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. To learn more about supported decisionmaking, see page 5 of this Guide.
- 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.

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.

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 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

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

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.

Mr. C’s story illustrates that even people with significant support needs can live long, healthy lives after transplantation if they have the right supports. 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, effective supports with medication management.

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.”¹ Evaluation of a patient’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.

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.

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;

1. 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.

- **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 Education 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 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.

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

Evaluating Likelihood of Transplant Success

Recent studies confirm that, provided they receive adequate support with post-operative care, individuals 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.³

3. 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.

Supporting Decision-making 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.”⁴

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.

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.⁵ 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

4. 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.

5. *Id.*

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.⁶ 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.

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.⁷

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.⁸ 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 communities. Moreover, patients with disabilities who received organ transplants may experience marked improvements in quality of life.⁹

7. 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/1-oregon-health-plan-is-unfair-to-the-disabled-659492.html>.

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

9. Ohta, T., Motoyama, O., Takahashi, K., Hattori, M., Shishido,

6. *Id.*

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.”¹⁰ Quality of health may include factors such as increased life expectancy, improved organ function, and reduction 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.¹¹

Conclusion

Individuals with intellectual, developmental, and psychiatric disabilities often experience significant barriers to accessing medically necessary organ transplantation. Barriers often arise from common misconceptions of disability or from lack of awareness of supports available to assist people with disabilities in adhering to post-operative treatment. Clinicians can reduce the effect of these barriers by familiarizing themselves with available sources of support for treatment management and medical decisionmaking, and by ensuring that their treatment decisions are based on assessments of medical benefit rather than on assumptions about the quality of disabled individuals’ lives.

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*, 47,5 18–527.

10. 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.

11. *Id.*