



Organ Transplant Discrimination Against People with Disabilities

Part of the Bioethics and
Disability Series



National Council on Disability

September 25, 2019

National Council on Disability (NCD)
1331 F Street NW, Suite 850
Washington, DC 20004

Organ Transplant Discrimination Against People with Disabilities: Part of the Bioethics and Disability Series

National Council on Disability, September 25, 2019

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National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

Letter of Transmittal

September 25, 2019

The President
The White House
Washington, DC 20500

Dear Mr. President,

On behalf of the National Council on Disability (NCD), I am pleased to submit *Organ Transplants and Discrimination Against People with Disabilities*, part of a five-report series on the intersection of disability and bioethics. This report, and the others in the series, focuses on how the historical and continued devaluation of the lives of people with disabilities by the medical community, legislators, researchers, and even health economists, perpetuates unequal access to medical care, including life-saving care.

Organ transplants save lives. But for far too long, people with disabilities have been denied organ transplants as a result of unfounded assumptions about their quality of life and misconceptions about their ability to comply with post-operative care. Although the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 (Section 504) prohibit discrimination on the basis of disability, organ transplant centers and medical professionals are often unaware that this prohibition applies to the organ transplant process.

NCD examined applicable federal and state laws, the disability-related policies of various organ transplant centers, and policies of the Organ Procurement and Transplantation Network (OPTN). Among other things, NCD found that discrimination continues to occur in the nine states that have enacted laws explicitly prohibiting such discrimination; that disabilities unrelated to a person's need for an organ transplant generally have little or no impact on the likelihood that the transplant will be successful; and that many organ transplant centers have policies that bar or caution against placing people with HIV, psychiatric disabilities, or intellectual and developmental disabilities (I/DD) on the waiting list to receive an organ transplant.

The lives of people with disabilities are equally valuable to those without disabilities, and healthcare decisions based on devaluing the lives of people with disabilities are discriminatory. *Organ Transplants and Discrimination Against People with Disabilities* provides an overview of the ways in which people with disabilities are discriminated against in the organ transplant process, an analysis of the protections provided, and the reasons underlying continued discrimination. The report describes why additional steps must be taken at the federal and state levels to clarify the law and educate organ transplant centers, physicians, and other medical professionals in order to prevent discrimination against people with disabilities. It concludes by outlining recommendations that can remedy such discrimination.

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NCD stands ready to assist the Administration, Congress and federal agencies to ensure that people with disabilities do not face discrimination in accessing life-saving organ transplants.

Respectfully,

A handwritten signature in black ink that reads "Neil Romano". The signature is written in a cursive style with a large, stylized "N" and "R".

Neil Romano
Chairman

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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Executive Summary

Purpose

People with disabilities are often denied equal access to organ transplants solely on the basis of their disability. These denials are frequently based on discriminatory assumptions that the lives of people with disabilities are of poorer quality than those of people without disabilities, and on misperceptions about the ability of people with disabilities to comply with postoperative care.

Despite the existence of studies debunking those misconceptions and the harrowing experiences of people with disabilities and their families, there are few resources that provide a nationwide overview of the problem and offer practical recommendations to federal and state policymakers. Similarly, despite the fact that discrimination against people with disabilities in the organ transplant process is barred by federal law and the laws of nine states, this type of discrimination has not been formally litigated. This report will examine these issues and provide policy recommendations.

Background

Donated organs in the United States are distributed via a federally run, national system rather than a private market because the National Organ Transplant Act of 1984 (NOTA) prohibits the buying and selling of organs.

The federally run system is called the Organ Procurement and Transplantation Network (OPTN), and it is run by the United Network for Organ Sharing (UNOS). NOTA established the

OPTN, which is overseen by the Department of Health and Human Services (HHS). UNOS has run OPTN as the sole contractor since 1986. UNOS and OPTN are treated as

synonymous and the two acronyms are often used interchangeably in this report.

There are six types of organs that can be donated through this system: the heart, lungs, kidneys, liver, pancreas, and intestine. UNOS/OPTN runs a national waiting list and creates the medical and geographic criteria that determine how the organs are matched with recipients. UNOS/OPTN also supervises two types of

UNOS/OPTN runs a national waiting list and creates the medical and geographic criteria that determine how the organs are matched with recipients.

organizations with significant influence over the organ transplantation process: organ transplant centers/hospitals and organ procurement organizations (OPOs).

Organ transplant centers and hospitals include transplant coordinators and other personnel who work with the patient and the patient's family, as well as the transplant surgeons who actually transplant the organ. These transplant centers themselves

decide whether to accept patients as candidates for transplant and whether to place patients on the national waiting list. To do so, organ transplant centers must first evaluate potential

patients to determine whether, in their view, an organ should be transplanted into that patient. Each organ transplant center has its own policies and practices governing how it decides which patients to accept and submit to the national waiting list.

Some of these policies list contraindications, which are facts about the patient and the patient's health that make it less likely that the patient will be accepted by the organ transplant center. There are "absolute contraindications," meaning the organ transplant center will never accept a patient with this characteristic, and "relative contraindications," meaning the organ transplant center is less likely to accept a patient with this characteristic. While UNOS/OPTN does not explicitly consider disability to be a contraindication to organ

transplant, some doctors and organ transplant centers still consider disability, and particularly mental health disabilities, to be either a relative or absolute contraindication to organ transplant, often despite evidence to the contrary.

Once a transplant center has agreed to transplant an organ into the patient, the patient is added to a national waiting list, which is managed by UNOS/OPTN. UNOS/OPTN has its own

specific policies for each organ that determine the priority level of patients on the waiting list. These policies typically prioritize the sickest patients first and do not specifically reference disability other than when a disability led

to the need for the transplant.

OPOs attempt to recruit new organ donors and provide donors with information and support. They also coordinate the organ donation process, ensuring that the organ is safely removed

and transported to its recipient.

Once an organ has been transplanted, the patient must adhere to a strict post-operative care regimen for the rest of

the patient's life. Postoperative care regimens may involve taking multiple medications at specific times each day, follow-ups with the transplant center, lifestyle changes, and the management of medication side effects or co-occurring conditions that are more common in organ transplant recipients. The assumption that people with disabilities will not be able to comply with postoperative care has caused

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UNOS/OPTN has its own specific policies for each organ that determine the priority level of patients on the waiting list.

disability to be considered a contraindication to organ transplant at many transplant centers despite the fact that people with disabilities, when provided with necessary supports, are no less likely to comply than people without disabilities.

Key Findings

- If a person has a disability that is unrelated to the reason a person needs an organ transplant, the disability will generally have little or no impact on the likelihood of the transplant being successful.
- If a person with a disability receives adequate support, the person's disability should also have very limited impact on the ability to adhere to a post-transplant care regimen. For some transplant candidates with disabilities, postoperative care would require careful coordination between the person's primary care and other providers, the person's circle of support, and the transplant team, but such support and coordination can be provided.
- Doctors, clinicians, and other medical experts, including those who are part of the organ transplantation process, differ in their perspectives with respect to whether people with disabilities should receive equal priority for organ transplants. Some doctors are concerned that people with intellectual and developmental disabilities

(I/DD) and mental health disabilities will be unable to comply with necessary post-operative care. Others may believe that the person's disability impacts the medical likelihood of transplant success, such as the graft or patient survival rate. Still other doctors have published significant research debunking myths and stereotypes about the medical suitability of people with particular types of disabilities for organ transplants.

- Disability-related policies vary greatly across organ transplant centers and across categories of disability. Many centers may have a current or past policy that treats HIV or AIDS, psychiatric disabilities, or intellectual and developmental disabilities (I/DD) as relative or absolute contraindications to transplant.
- While rarely invoked in this context, the Americans with Disabilities Act and Section 504 of the Rehabilitation Act prohibit organ transplant centers from discriminating on the basis of disability. Limited enforcement is likely due to the time-sensitive nature of organ transplant decisions, and the fact that federal litigation can take years to resolve. The lack of federal guidance may also contribute to the lack of litigation under federal antidiscrimination laws.
- Nine states have laws banning organ transplant discrimination. Newer state laws often, but not always, include more

The assumption that people with disabilities will not be able to comply with postoperative care has caused disability to be considered a contraindication to organ transplant at many transplant centers . . .

protections against discrimination than older laws. Despite the existence of both state and federal antidiscrimination laws, disability-based discrimination in the organ transplant process continues to occur.

- UNOS/OPTN has proposed organ procurement policies that pose serious risk to people with disabilities. Existing policies and practices fail to protect people with disabilities from being pressured to donate organs, and some recent OPTN proposals would weaken the few protections that currently exist.
- The fair allocation of organs is a complex and much-debated ethical issue among bioethicists and other stakeholders. At the heart of the debate are concerns about scarcity of transplantable organs and societal beliefs about the worth of the life of a person with a disability. While there is no broad consensus, most individuals interviewed for this report believe that organs should be allocated purely on the basis of medical necessity, rather than a subjective analysis of the individual's quality of life before or after the transplant.

Despite the existence of both state and federal antidiscrimination laws, disability-based discrimination in the organ transplant process continues to occur.

Key Recommendations

The Department of Justice (DOJ), in conjunction with the Department of Health and Human Services (HHS)

- DOJ, in conjunction with HHS, should release guidance and provide technical

assistance clarifying that Titles II and III of the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 apply to organ transplant centers and hospitals. This guidance and technical assistance should detail the obligations of organ transplant centers and hospitals to avoid discriminating on the basis of disability in the organ transplant process and advise organ transplant centers how to ensure their evaluation of candidates complies with federal law. This guidance and technical assistance should:

- Emphasize that the United Network for Organ Sharing (UNOS)/Organ Procurement and Transplantation Network (OPTN) should ensure that its policies are consistently applied in a manner that avoids discrimination.
- Explicitly state that making assumptions regarding the post-transplant quality of life for people with disabilities violates federal law.
- Make clear that the ADA and Section 504 apply throughout the organ transplant process, including informal eligibility determinations, such that disability should only be taken into account to the extent that it can be clearly shown to be likely to impair successful transplantation.
- Encourage priority review of any cases brought challenging discrimination on the basis of disability in the organ transplant

context in acknowledgment of the time-sensitive nature of a transplant denial.

- Delineate organ transplant center and physician responsibilities under Section 504 and the ADA to make reasonable modifications in their policies, practices, and procedures for people with disabilities seeking transplantation, and to ensure effective communication with those people including by providing, among other things, accessible digital and print materials for patients and families. Reasonable modifications should include ensuring that a patient has the necessary support services to comply with postoperative care.
- DOJ and HHS should also provide technical assistance to organ transplant centers and physicians in complying with the foregoing obligations. Issuing guidance and providing technical assistance would increase the likelihood that the application of the ADA, Section 504, and Section 1557 to the organ transplant process would be understood and that compliance with these laws would

prevent disability discrimination in the organ transplant process. Organ transplant center policies that discriminate could more easily be challenged, and it could become easier to address the hidden discrimination inherent in the evaluation process.

UNOS/OPTN

- UNOS/OPTN should ensure that individuals and families are able to make informed decisions about the withdrawal of life-sustaining treatment prior to and independent from any contacts from organ procurement organizations.

State Legislatures

- State legislatures should adopt clear and detailed laws prohibiting disability-based discrimination in the organ transplantation process, including complaint procedures, with expedited priority review for these complaints and robust remedies for discrimination, especially considering that timeliness can be a matter of life and death in cases involving organ transplants.

Acronym Glossary

ADA	Americans with Disabilities Act
ALS	amyotrophic lateral sclerosis
ASAN	Autistic Self Advocacy Network
DALYs	Disability Adjusted Life Years
DOJ	Department of Justice
DREDF	Disability Rights Education & Defense Fund
EMTALA	Emergency Medical Treatment and Active Labor Act
GWU	George Washington University
HCBS	home and community-based services
HHS	Health and Human Services
I/DD	intellectual and developmental disabilities
LTTS	long-term services and supports
LVAD	left ventricular assist device
MELD	Model for End Stage Liver Disease
NCD	National Council on Disability
NIDILRR	National Institute on Disability, Independent Living, and Rehabilitation Research
NOTA	National Organ Transplant Act of 1984
OCR	Office for Civil Rights
OPO	organ procurement organizations
OPTN	Organ Procurement and Transplantation Network
PCC	Physicians for Compassionate Care
QALYs	Quality Adjusted Life Years
SAMHSA	Substance Abuse and Mental Health Services Administration
UMMC	University of Maryland Medical Center
UNOS	United Network for Organ Sharing

Glossary

Contraindication: An indication that a particular candidate for an organ transplant is unsuitable for organ transplantation. Contraindications are usually identified by organ transplant centers during the evaluation process described in Chapter 1.

Graft survival: The probability of the organ itself continuing to function at some specific point after transplantation. For example, if four kidneys are transplanted into four patients and two of the transplanted kidneys fail after a year (forcing these two patients to go back on dialysis), this would reflect a 50 percent 1-year graft survival rate.

Medical noncompliance. The inability or failure to follow a prescribed course of treatment. While some disabilities may be related to a higher rate of medical noncompliance after organ transplant unless the person with a disability receives sufficient supports, medical noncompliance is not necessarily linked to disability.

Organ Procurement Organization (OPO): Centers for Medicare and Medicaid Services (CMS)-designated organizations that have two roles: (1) increasing the number of registered donors in the area in which they serve; (2) coordinating the actual donation and transport of the donated organ once the organ becomes available for donation (either via the donor's consent or the donor's death, depending on the organ).

Organ Procurement and Transplantation Network (OPTN): The United States' organ transplant network. All organ transplant centers, **organ procurement organizations (OPOs)**, and others involved in the process of transplanting organs are members. OPTN coordinates the entire organ transplantation process. It runs the computerized system used to match donated organs to recipients, creates the medical criteria used to determine when each person on the national waiting list receives an organ, and provides medical and ethical guidance to organ transplant centers and OPOs.

Organ transplantation: The process of transplanting a solid organ (such as a liver, kidney, or heart) from one body into another, as well as ensuring that the body accepts the transplant.

Patient survival: The likelihood that the recipient of an organ transplant will be alive at some specific point after transplantation. For example, if four hearts are transplanted into four patients and only two of them survive after a year, this would reflect a 50 percent 1-year patient survival rate.

Renal transplantation: The transplantation of a kidney.

United Network for Organ Sharing (UNOS): The nonprofit organization that acts as the sole contractor managing the United States' national organ transplant waiting list and the Organ Procurement and Transplantation Network (OPTN).



The fair allocation of organs is a complex and much-debated ethical issue among bioethicists and other stakeholders. At the heart of the debate are concerns about scarcity of transplantable organs and societal beliefs about the worth of the life of a person with a disability. While there is no broad consensus, most individuals interviewed for this report believe that organs should be allocated purely on the basis of medical necessity, rather than a subjective analysis of the individual's quality of life before or after the transplant.

Introduction

One of the most persistent and enduring debates in the field of bioethics and health is how best to allocate scarce medical resources. Medical resources—such as medications, treatments, hospital beds, or supplies—are considered scarce when there is a limited supply but a high demand. Medical resource scarcity often results in the need to prioritize some patients’ needs over those of others, even though such prioritization may deny some patients access to lifesaving care.

Transplantable organs are among the scarcest of all medical resources. According to data from UNOS, there are currently more than 113,000 people on the national transplant waiting list, and over 6,500 people died while on the waiting list in 2017.¹ Due to the scarcity of transplantable organs and the life-or-death implications of organ allocation decisions, fair allocation of transplantable organs is critically important.

People with disabilities are, however, frequently denied equal access to organ transplants. Denials of equal access may result from organ transplant centers’ written and unwritten policies excluding people with

disabilities as candidates for transplant, and even refusing to evaluate a particular person’s medical suitability for an organ transplant because of the person’s disability. Discrimination by physicians and organ transplant centers also may result in people with disabilities being given lower priority for transplants than people without disabilities.

This report discusses the history, causes, and bioethical implications of disability discrimination in organ transplantation and recommends approaches to reduce the likelihood of such discrimination.

According to data from UNOS, there are currently more than 113,000 people on the national transplant waiting list, and over 6,500 people died while on the waiting list in 2017.

How Does the Report Define “Disability”?

This report uses a broad definition of the term “disability” as it is defined in the Americans

with Disabilities Act (42 U.S.C. § 12102). Under that definition, a disability is any physical or mental impairment that substantially limits a “major life activity” or “major bodily function” (for example, a physical task such as eating, drinking, or moving or a cognitive task such as reading, concentrating, or thinking).² A wide array of individuals are “people with disabilities” covered by the ADA, including people with intellectual and developmental disabilities (I/DD); people

with psychiatric disabilities; people with physical disabilities such as mobility-related impairments, deafness, and visual impairments; and people with chronic ailments or diseases (such as being HIV-positive or having AIDS). Most of the policies the NCD research team examined for this report specifically addressed people with I/DD, people with psychiatric disabilities, and people who are HIV positive or have AIDS. This report therefore focuses on the impact of organ transplantation policies on these three populations of people with disabilities.

Summary of Methodology

In order to present a clear and comprehensive picture of disability discrimination as it manifests at each stage of the organ transplant process, the NCD research team consulted stakeholders (including doctors, clinicians, and people with disabilities and their families); federal laws pertaining to disability as well as specific state laws banning disability discrimination in organ transplantation; organ transplant center policies; UNOS/OPTN guidelines; and relevant scholarly articles from legal, medical, and bioethical perspectives.

Qualitative Data

To understand the day-to-day impact of unequal access to organ transplants on people with disabilities, NCD conducted seven in-depth interviews with a variety of stakeholders. Our interviews were with representatives of advocacy organizations who serve people with disabilities, a clinician who assists people with disabilities in acquiring the services and supports they need to comply with postoperative care, a bioethicist with expertise in ethical issues relating to organ transplantation, and people who have been

denied access to an organ transplant on the basis of disability. These interviews helped demonstrate how organ transplant discrimination is experienced by people with disabilities and supported NCD's conclusions in this report. NCD was unable to interview any executives or directors of organ transplant centers.

Quantitative Data

NCD used the UNOS/OPTN member directory to determine how many organ transplant centers there are in each geographic region as assigned by UNOS/OPTN, as well as how many organ transplant centers exist in states with organ transplant discrimination laws.

Literature Review

NCD conducted a comprehensive literature review of federal laws, statutes, and policies affecting people with disabilities, with a particular focus on how these laws might impact organ transplantation. NCD acquired and reviewed the text of all nine state laws banning disability discrimination in the organ transplant context, as well as the text of pending legislation in two states. NCD also conducted an extensive search on commonly used legal databases for law review articles and law journal excerpts pertaining to organ transplantation. To obtain information on how organ transplant centers view disability, as well as the perspectives of medical and ethical experts on organ transplants, NCD reviewed articles from research journals, bioethics journals, and news articles pertaining to organ transplantation and disability.

Limitations

Three of the seven people NCD interviewed were the family members of people with disabilities

who were discriminated against at some point during the organ transplantation process. All three individuals interviewed were part of high-profile cases that were covered in depth by the national and local press. In addition, all of the people who were available for interviews had family members with I/DD and one had a family member with co-occurring I/DD and psychiatric disability. They therefore did not represent the full diversity of individuals who have been subject to organ transplant discrimination.

NCD's research team has attempted to supplement its qualitative data by searching for news articles, research articles, and other information pertaining to people with other disabilities and includes that information in this report.

The qualitative data NCD gathered represents only the views of specific individuals who have been subjected to discrimination and complements rather than supplants the quantitative data and literature review.

Chapter 1: The Organ Transplantation Process and Discrimination on the Basis of Disability

Introduction

OPTN is under the jurisdiction of United States Department of Health and Human Services (HHS)³ and is managed by UNOS.⁴ These entities supervise organ transplant centers, which are components of larger hospitals.⁵ UNOS/OPTN also supervises organ procurement organizations (OPOs).

As explained throughout this report, disability discrimination, particularly discrimination against people with psychiatric disabilities and people with I/DD, can be found at almost all stages of the organ transplantation process.

A Brief Overview of the Organ Transplant Process

There are four steps to the organ transplant process:⁸

1. The patient's physician refers the patient to an organ transplant center.
2. The organ transplant center evaluates the patient's eligibility for an organ transplant.
3. If the organ transplant center determines that the patient is eligible, the organ transplant center places the patient on the national waiting list.

4. If a match is found, the transplant center carries out transplantation of that organ.

When a patient is referred by a physician in Step 1, the patient must then be evaluated by one of the nation's 252⁶ organ transplant centers to determine whether the patient meets that transplant center's criteria for an organ transplant.⁷ Although the evaluation process is often initiated after the patient's physician provides the patient with a referral to a specific local organ transplant center, a referral from a physician is not necessary in order to receive an evaluation, and the patient (or the patient's legally authorized guardians or decision makers) may choose to contact whichever transplant center best meets the patient's needs (often referred to as self-referral).⁹

The typical evaluation consists of various medical tests to determine current health status and evaluations of the patient's psychological health, financial situation, and social supports.¹⁰ The exact process varies among transplant centers, as each center determines its own criteria for evaluating patients.¹¹ Each organ transplant center is required by law to provide its specific guidelines and criteria for inclusion and exclusion of patients as candidates for transplant

to both OPTN and the local OPO with which it is affiliated.¹²

The transplant team may include:

- transplant physicians (doctors who manage the patient’s medical care, testing, and medications);
- transplant surgeons (the doctors who actually perform the organ transplantation);
- financial coordinators (who work with the patient and hospital administrators with respect to the financial aspects of the patient’s care);
- transplant coordinators (who are responsible for the patient’s evaluation, treatment, and follow-up care); and
- social workers (who help patients prepare for transplant mentally and emotionally).¹³

The evaluation stage is typically when the transplant team learns whether the patient has a disability other than the condition that led to the need for a transplant. Sometimes, however, the patient or the patient’s family has already provided this information during earlier conversations with the transplant team.

Following the evaluation, the transplant team determines whether or not they will accept the patient as a candidate for transplant.¹⁴ The organ transplant team’s decisions are typically informed by guidelines produced by recognized experts in the field,¹⁵ such as the International Society for Heart and Lung Transplantation’s heart transplantation criteria,¹⁶ as well as the policies of their particular organ transplant center, as

discussed above. On occasion, these criteria and policies do in fact reference specific disabilities and may even refer to specific types of disabilities as relative contraindications (e.g., HIV/AIDS), factors that weigh against transplanting an organ into a specific candidate.¹⁷ The transplant team itself retains a great deal of discretion when evaluating which individuals it will recommend for transplant, and therefore may consider additional factors not included in these criteria.¹⁸

If the transplant team decides that they will accept the patient as a candidate for transplant, the transplant team places the candidate on the OPTN national waiting list.¹⁹ All candidates for transplant must be registered on the OPTN waiting list²⁰ pursuant to NOTA.²¹ Patients with

a living, known donor are often able to get off of the waiting list more quickly because they do not have to wait for an organ from a deceased donor.²²

The transplant team itself retains a great deal of discretion when evaluating which individuals it will recommend for transplant . . .

OPTN sets medical criteria specific to each organ that govern the allocation of donated organs to recipients on the national waiting list.²³ In general, these criteria focus on four concerns: (i) medical compatibility between the donor and organ recipient (for livers, this would include blood type and liver size),²⁴ (ii) how long the patient has been on the waiting list, (iii) the distance between the donated organ or living donor and the recipient, and (iv), for some organs such as livers and hearts, how urgently the transplant is needed.²⁵ Medical urgency is taken into account with respect to some organs and not others because with some organs, such as kidneys, it is possible to survive for a longer period of time without receiving a

transplant than is the case with other organs (e.g., through the use of dialysis instead of a kidney).²⁶

Where medical urgency is one of the medical criteria for transplant, however, it is one of the most important factors, as it determines how long the patient can afford to wait for an organ before the patient's life is at risk. The patients are therefore "ranked"—that is, prioritized on the waiting list—by the OPTN in the order of their medical urgency and time spent on the waitlist at a specific priority level.²⁷ For example, for liver transplants, "[m]edical urgency is determined by" the liver patient's Model for End Stage Liver Disease (MELD) score.²⁸ Each patient's MELD score, time on the waitlist, and geographical distance from the organ places them within one of thirteen priority categories, of which the designations 1A and 1B are "the most medically needy."²⁹ Local and regional 1A and 1B candidates are at the top of the waitlist, followed by eleven other categories that rotate among local, regional, and national candidates, where candidates are ranked based on descending MELD score and length of time on the waitlist.³⁰ None of the criteria used by OPTN mention or consider any unrelated disability in the organ recipient (such as an intellectual disability, psychiatric disability, or HIV) to be relevant to the allocation decision.³¹

OPTN's criteria are occasionally amended or changed. For example, OPTN's criteria for the allocation of hearts originally divided patients on the waiting list into three designations based on medical urgency, conveyed here in descending order of urgency: 1A, 1B, and 2.³² As of October 2018, patients are now divided into six statuses, and patients with the most urgent need may receive hearts transported

from up to 500 miles away (farther than they would have been transported under the older guidance).³³

To match donor organs to patients, OPOs will "typically [access] the computerized organ matching system, [enter] information about the donor organs, and [run] the match program" unless the OPO requests that OPTN's Organ Center handle the matching process or "there is a need to identify" a perfectly matched donor and recipient for a kidney transplant.³⁴ The computerized program generates a list of possible recipients for each donated organ and prioritizes the recipients based on "objective criteria (i.e., blood type, tissue type, size of the organ, medical urgency of the patient, time on the waiting list, and distance between donor and recipient)."³⁵ The specific criteria considered depend on the type of organ being transplanted,³⁶ but information in the computer system is entered by transplant centers, and OPOs rely on their determinations when finding a match.

Once the computer generates the list of potential recipients, the OPO's procurement coordinator contacts the transplant surgeon caring for the highest-ranked patient on the list and offers the organ to that patient.³⁷ If the transplant surgeon decides that the organ is not "suitable" for that patient, based on factors including "the donor's medical history and the current health of the potential recipient," the transplant surgeon can turn the organ down.³⁸ If the organ is turned down, the procurement coordinator then continues down the list until one of the transplant centers accepts the organ.³⁹ UNOS is constantly working with transplant centers to find ways for less-than-perfect organs to still be effective for transplants, including

organs from donors with disabilities or treatable illnesses.⁴⁰

How Many Organ Transplant Centers Are There?

According to the OPTN member directory, as of March 2019, there were 252 organ transplant centers in the United States.⁴¹ All organ transplant centers are members of the OPTN.⁴² As transplant centers are subdivisions of medical centers or hospitals, the entire hospital or medical center is listed in the OPTN member directory.⁴³

OPTN divides the United States into geographic regions in order to better facilitate efficient transplantation of organs.⁴⁴ There are 11 regions total, and 58 OPOs that assist with the transport of donated organs to their recipients. OPOs will be discussed in more detail in the section, “Organ Procurement Policies and Practices and Their Effect on People with Disabilities.” Table 1 in the Appendix identifies the states in each of the 11 regions and shows how many organ transplant centers are located in each geographic region. Table 2 in the Appendix lists the number of organ transplant centers located in each state, as well as the geographic region in which each state is located.

Disability Discrimination by Physicians

Physicians, including both personal physicians and physicians working for organ transplant

centers, sometimes refuse to recommend that a person with a disability receive an organ transplant on the basis of that person’s disability, even when the disability should not impact the success of an organ transplant. In these cases, personal physicians may refuse to provide a referral for the patient to receive an evaluation at a transplant center or physicians working for organ transplant centers may refuse to evaluate a referred patient or to place that patient on the waiting list following the evaluation.

This discrimination can be explicit and deliberate, such as a physician directly stating that he or she is not recommending a person

Physicians . . . sometimes refuse to recommend that a person with a disability receive an organ transplant on the basis of that person’s disability, even when the disability should not impact the success of an organ transplant.

with a disability be placed on the waiting list for an organ transplant because of that disability. But it is also possible for a physician’s prejudice toward people with disabilities to influence decision making in more subtle ways. For instance, a physician

could, because of disability-related stereotyping, prejudice, or unfamiliarity with people with a disability, mistake symptoms of organ failure for a psychological ailment or a more minor physical ailment.

To better understand physician discrimination, NCD interviewed Karen Corby for this report. Karen Corby is the mother of Paul Corby, an autistic man with psychiatric disabilities who was denied an organ transplant. Karen Corby described a series of doctors’ visits in which each doctor who evaluated Paul Corby insisted that his worsening physical condition was merely a symptom of anxiety.⁴⁵ According to

Paul’s mother, while the doctors initially thought Paul’s symptoms could signal heart problems, they began saying his symptoms were due to anxiety once they learned that Paul has autism.⁴⁶ This continued for 3 months, through visits to doctors’ offices or the hospital for vomiting, chest pains, or persistent cough.⁴⁷ Despite these symptoms, rapid heartbeat, and inability to eat, Paul’s doctors never tested his heart and continued to say Paul’s symptoms were caused by anxiety.⁴⁸

Physicians may also fail to recommend standard therapies or treatments to people with disabilities that they would recommend immediately to patients without disabilities.

For example, the NCD research team interviewed Jessica Sunshine Bodey, the mother of Lief O’Neill, an 11-year-old boy in critical need of a heart transplant. While the family was informed that Lief was being denied a transplant because he had autism—a decision they found discriminatory—Lief’s medical team also did not inform them that bridge therapies were available to extend his life while he waited for a transplant.⁴⁹ The bridge therapy in question, a left ventricular assist device, or LVAD, is considered a standard “bridge therapy” on the way to receiving a transplanted heart.⁵⁰ Lief ultimately needed four consecutive LVADs to survive.⁵¹

Lief’s experience is not unique: people with disabilities often do not receive the services and supports they need in the organ transplantation

process. A 2004 survey, the most recent one available, found that only 52 percent of people with disabilities who requested a referral to a specialist regarding an organ transplant evaluation actually received a referral, while 35 percent of those “for whom a transplant had been suggested” never even received an evaluation.⁵² NCD was unable to find a study that specifically examined organ transplant referrals and evaluation rates for people without disabilities, but two studies that looked at transplant populations as a whole suggest that people without disabilities receive referrals and evaluations at higher rates than people with

52 percent of people with disabilities who requested a referral to a specialist regarding an organ transplant evaluation actually received a referral, while 35 percent of those “for whom a transplant had been suggested” never even received an evaluation.

disabilities. One study examining patients with liver disease at a Veterans Affairs center between 2002 and 2003 found that, while many barriers to transplantation exist, of patients who received a referral, 75 percent received an evaluation.⁵³ Another study found that between

92.1 and 95.5 percent of patients deemed appropriate for evaluation for kidney transplant received a referral and that of those, 81.4 percent were placed on the transplant waiting list.⁵⁴

Disability Discrimination by Organ Transplant Centers

The primary forms of disability discrimination practiced by organ transplant centers are (1) the refusal to evaluate a person with a disability as a candidate for transplant and (2) the refusal to place a person with a disability on the national organ transplant waiting list.

Refusal to Evaluate a Person with a Disability as a Candidate

In some cases, organ transplant centers may categorically refuse to evaluate a patient with a disability as a candidate for transplant. Christine Rivera, the mother of Amelia Rivera—a 3-year-old girl with a developmental disability who needed a kidney transplant—stated that the organ transplant center that evaluated Amelia made no attempt to determine her medical suitability for transplant.⁵⁵ Instead, the doctor explained that the transplant center would never place her on the waiting list because she had an intellectual disability.⁵⁶ Ms. Rivera explained that one of her own family members would donate the organ, meaning there would be no need to place her daughter on the OPTN waiting list, but the doctor continued to vehemently refuse to consider an organ transplant for her daughter.⁵⁷

Disability Discrimination During the Evaluation

As discussed in Chapter 3, many organ transplant centers have written policies or practices that arguably fail to follow federal law by facially discriminating on the basis of disability. That said, there are few empirical studies analyzing how organ transplant centers actually evaluate patients for transplantation, particularly with respect to how any particular disability influences which patients are selected. A study conducted by Stanford University in 2008, for example, showed that 62 percent of pediatric transplant centers tended to make “eligibility decisions based on disability . . . informally, making

discrimination difficult to show.”⁵⁸ A more recent 2017 study found that no comprehensive study of the patient selection criteria for US-based transplant programs for people with psychiatric disabilities had been conducted in over 20 years.⁵⁹ But it appears that many transplant centers, including those that either lack written policies or have written nondiscriminatory policies, discriminate on the basis of disability when evaluating patients for organ transplants.

Disability discrimination persists in the evaluation process because, in spite of evidence to the contrary,⁶⁰ many physicians still view HIV and AIDS, as well as intellectual, developmental, or psychiatric disabilities, as relative or absolute contraindications to transplant, and many

In some cases, organ transplant centers may categorically refuse to evaluate a patient with a disability as a candidate for transplant.

transplant centers continue to consider the disabilities of organ transplant candidates when making determinations about which candidates

are eligible to be placed on the waiting list for a transplant.⁶¹ This view of disability as an absolute or relative contraindication to an organ transplant reveals pervasive biases within the medical community demonstrating that disability discrimination during the evaluation process is a problem.

For instance, a 2006 National Public Radio story found that about 60 percent of transplant centers report having serious reservations about giving a kidney to someone with a mild to moderate intellectual disability.⁶² A subsequent 2008 survey of pediatric transplant centers found that 43 percent always or usually consider intellectual disabilities an absolute or relative contraindication to transplant due to assumptions

about quality of life, concerns regarding “compliance or long-term self-care,” “financial concerns,” and “the functional prognosis of the delay itself.”⁶³ The patient’s “degree” of and type of I/DD mattered in the 2008 study: while 40 percent of transplant programs reported that I/DD would “never” be an absolute contraindication to transplant, 21 percent of the programs reported that “severe delay” was an absolute contraindication and 19 percent reported that “profound delay” was an absolute contraindication.⁶⁴

There may have been small improvements over the last few decades in how candidates with I/DD are evaluated for organ transplants. Prior to the 1990s, intellectual disability was typically regarded as a contraindication to organ transplant.⁶⁵ In 1995, 65 percent of second-year medical students viewed Down syndrome as a contraindication to heart transplant and only 31 percent rated it as irrelevant.⁶⁶ By 2013, in a study of liver transplant providers, 82 percent did not see “mild cognitive disability” as a contraindication to transplant at all, and 42.6 percent did not see “moderate cognitive disability” as a contraindication.⁶⁷ All but 11 percent of these transplant centers, however, saw “severe cognitive disability” as a contraindication.⁶⁸ Indeed, a 2018 article found that providers and medical associations continue to view I/DD as a contraindication for organ transplants for pediatric patients because of assumptions about the patient’s quality of life, lifespan, and post-transplant compliance.⁶⁹

... [A]bout 60 percent of transplant centers report having serious reservations about giving a kidney to someone with a mild to moderate intellectual disability.

The same 2013 survey of liver transplant providers found that while most organ transplant centers did not consider psychiatric disability to be an absolute contraindication to transplant, they did rank it among the top three “most controversial” characteristics of patients.⁷⁰ Provider opinions also differed based on whether the person with the psychiatric diagnosis was “stable” or “unstable,” which appears to refer to the degree to which the person managed symptoms, and the number of suicide attempts.⁷¹ For example, when the patient had “acute liver failure,” a diagnosis of “major psychiatric illness, stable” was not considered a contraindication by 57.6 percent of respondents, was viewed as a relative contraindication by 41.2 percent of respondents, and was viewed as an absolute contraindication by 1.2 percent of respondents.⁷² But the diagnosis of “major psychiatric illness, unstable” was viewed as an absolute contraindication by 39.8 percent of respondents, and as a relative contraindication by another 52.9 percent of respondents.⁷³

The belief that patients with psychiatric disabilities will be unable to comply with post-transplant regimens, including medication and follow-up appointments may “lead to the creation of eligibility criteria that bar patients with psychotic disorders from [transplants]” despite the fact that “studies demonstrate that the overall noncompliance rate of psychiatric patients falls within the range of noncompliance seen in the larger transplant population.”⁷⁴ Some medical professionals also view psychiatric disabilities as a contraindication for organ

transplants based on the belief that people with psychiatric disabilities enjoy a lower quality of life and thus should not benefit from a resource as scarce as organs.⁷⁵

Patients who are HIV-positive are less likely to face discrimination on the basis of disability in the evaluation

process than in the past. Perhaps because the life expectancy and prognosis of those with the condition have improved dramatically.⁷⁶

Since it was first discovered, a diagnosis of HIV-positive is no longer considered an absolute contraindication by most organ transplant centers.⁷⁷ But it is worth noting that 54.6 percent of respondents to the 2013 survey still considered HIV-positive status to be a relative contraindication, suggesting that HIV-positive status remains a factor that weighs against a candidate being accepted as a patient.⁷⁸

The informal nature of evaluations for organ transplants may also lead to discrimination on the basis of disability. A 2009 study of pediatric transplant centers stated that 69 percent of those surveyed reported that their transplant center's process for evaluating the relevance of neurodevelopmental disability to eligibility for an organ transplant, on a scale of 1 to 5, was mostly

"informal, implicit, or unstated" as opposed to "formal, explicit, and uniform."⁷⁹ This "lack of uniformity" in organ transplant center guidelines could produce situations in which a patient could be rejected by one organ transplant center but accepted by another, even in the same state.⁸⁰

Yet patients may not realize they can "shop" for transplant centers in the same way the US healthcare system allows them to "shop" for doctors; others may not be able to do this

because of health, financial, or transportation issues.

Rectifying discrimination on the basis of disability in the organ transplant process may involve imposing additional procedural requirements on organ transplant centers to

prevent inconsistent, subjective decision making that facilitates discrimination. David Magnus, a professor of Medicine and Biomedical Ethics at Stanford University, argues that the solution to this opaque kind of decision making is not to merely say, "You shouldn't discriminate," but rather to standardize or specify the evaluation process transplant centers

must use so that psychosocial assessments of transplant candidates are as objective and evidence-based as possible.⁸¹

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Organ Procurement Policies and Practices, and Their Effect on People with Disabilities

Disability-based discrimination occurs not only in the allocation of organs, but also in the procurement process. Existing policies have not adequately protected individuals and families from being contacted and even pressured by OPOs prior to a decision that life support will be withdrawn, even in cases involving ICU patients who recovered and went home.⁸² The newly injured population is particularly vulnerable to abusive organ procurement policies because their recent trauma and uncertain future makes them susceptible to “the message that their death would mean more to the people around them than their life.”⁸³ People with disabilities in intensive care units whose prognoses are uncertain are likewise vulnerable to abuse in organ procurement practices.⁸⁴ In the initial phase of an injury or a serious exacerbation of a chronic or progressive condition, healthcare decision making that could lead to death may be under consideration. Conditions that involve ongoing interventions, such as a feeding tube or even ongoing critical medications, may also involve decisions that lead to death. These situations all create potential for organ donation and, thus, activities by OPOs.

The newly injured population is particularly vulnerable to abusive organ procurement policies because their recent trauma and uncertain future makes them susceptible to “the message that their death would mean more to the people around them than their life.”

Discrimination in organ procurement is further complicated by the fact that doctors have varying opinions about what medically constitutes brain death . . .

Colleen Burns, a woman with a history of depression who had overdosed on a toxic cocktail of drugs, provides one such example of this abuse. After her overdose, Colleen was declared brain dead, and was on the operating table after her family had agreed to allow organ donation when she woke up just before the process began.⁸⁵ The hospital missed several signs that Colleen’s brain was still functioning, including that “her nostrils flared, her lips and tongue moved, she was breathing ‘above the ventilator’ (meaning, taking breaths of her own accord) [, a]nd when a nurse performed a reflex test, scraping a finger along the bottom of Burns’ foot, the woman’s toes curled inward.”⁸⁶ Doctors also never ordered repeat CT scans, “inexplicably and inaccurately said that she suffered from cardiac arrest” although she had not, and, most critically, given that Colleen’s hospitalization was caused by a drug overdose, “failed to measure whether the drugs she had taken still lingered in her system, preventing her from exhibiting even the most primitive reflexes expected of someone with brain activity.”⁸⁷

Discrimination in organ procurement is further complicated by the fact that doctors have varying opinions about what medically constitutes brain death, including the minimally

acceptable observation period to determine that brain function has irreversibly ceased.⁸⁸ This uncertainty is heightened by policies surrounding determinations of brain death in hospitals, which vary widely and do not necessarily conform to accepted best practices.⁸⁹

A survey of almost 500 hospitals found that most do not require that someone with a background in neurology or neuroscience be present when brain death determinations are made, nor do they require the determination to be made by the patient's attending physician.⁹⁰ This lack of uniformity and precision in hospital policies and practices increases the likelihood of abuse, or at the very least, mistaken determinations of brain death, as in the case of Colleen Burns.

There have been several recent OPTN proposals and professional articles pushing to weaken protections for conscious people with disabilities⁹¹ and explicitly encouraging individuals to see themselves as sources of organs to save others.⁹² In 2017, the UNOS/OPTN Ethics Committee released a living donation white paper that recommended modifying OPTN policies for informed consent, psychosocial and medical evaluation, and follow-

up used to determine the eligibility of a living donor in order to "accommodate" donations from people with certain fatal diseases (such as ALS and cystic fibrosis).⁹³ Due to the white paper's

statements concerning assisted suicide and the psychological benefits of donation for people with fatal diseases and their families or communities, advocates expressed concern that such revised criteria may promote accepting living donors with fatal diseases who feel like they are a burden or

who are seeking enhanced meaning by donating when such reasons would not be acceptable for other living donors.⁹⁴ The proposal also suggested that scrutiny of donor deaths should consider circumstances in which the donor's death was a result of the person's "underlying

disease, and not . . . the living donation process itself" differently than circumstances in which the donor's death was related to the donation process.⁹⁵

Other policy proposals discussed in professional articles, such as Organ Donation Euthanasia, which would allow for

the removal of organs from patients whose poor prognoses would make them eligible to be withdrawn from life support under general anesthesia,⁹⁶ may also serve to exacerbate

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the pressures placed on people with these disabilities and their families regarding organ donation.⁹⁷ UNOS/OPTN has also not established protocols to ensure that organs are not procured before a conscious potential donor has received appropriate psychological counseling and supports to live. For these vulnerable patients, this lack of protocols and policies may make them more susceptible to suggestions of the benefits of organ donation.

It is worth noting that recent developments in organ procurement have significantly increased the number of organs available to people with HIV awaiting transplant. While the first transplants of organs (a liver and kidney) from a deceased donor with HIV to HIV-positive recipients occurred in 2016,⁹⁸ living donation of kidneys “was considered too dangerous because the infection and the medications that control it increase the chances of kidney disease.”⁹⁹ In 2017, however, Johns Hopkins conducted a study on 42,000 people¹⁰⁰ that found that those “with

well-controlled HIV have basically the same risks as those without HIV and are healthy enough to donate kidneys” because “new antiretroviral drugs are safe for the kidney.”¹⁰¹ In light of those findings, the first living kidney transplant between people with HIV was performed at Johns Hopkins in March of 2019, with the surgeons performing the surgery hoping that its success “will expand the pool of available organs and help change

perceptions of HIV.”¹⁰²

The donor, Nina Martinez, spoke of her choice to donate in similar terms, saying, “Society perceives me and people like me as people who bring death. . . . And I can’t figure out any better way

to show that people like me can bring life.”¹⁰³

In Chapter 6, “Recommendations,” NCD offers several recommendations for the Department of Health and Human Services that may help people with disabilities make their own informed choices about organ donation while preventing them from being discriminated against in the organ procurement process.

UNOS/OPTN has also not established protocols to ensure that organs are not procured before a conscious potential donor has received appropriate psychological counseling and supports to live.

Chapter 2: Ethical and Medical Perspectives on Organ Transplants for People with Disabilities

Medical Perspectives on Organ Transplants for People with Disabilities

Medical Practitioners and Transplants for People with Disabilities

Medical practitioners have generally voiced one of two opinions in the research literature about people with “mental disabilities” (including intellectual and developmental disabilities [I/DD] and/or psychiatric disabilities):

Opinion 1: They accept patients with mental disabilities on a case-by-case basis, but may have significant reservations about transplanting organs into these patients due to concerns about the patient’s potential inability to follow a post-transplant regimen.¹⁰⁴

Opinion 2: They believe patients with mental disabilities should never be excluded from an organ transplant on the basis of disability and argue for increased equity with respect to these patients.¹⁰⁵

As explained in Chapter 3, some organ transplant centers have written policies describing psychiatric disabilities as absolute contraindications to organ transplant. But with respect to I/DD, NCD did not find examples of

doctors or clinicians who have opined that people with I/DD should never receive organ transplants. This may be because doctors rarely voice this opinion publicly: when one woman in Oklahoma with I/DD was denied a kidney, the transplant center that denied her refused to talk about the case with journalists investigating the denial of her transplant, instead citing confidentiality issues.¹⁰⁶

Doctors at other organ transplant centers and hospitals maintain that they do not and never have used specific mental disabilities to exclude patients from organ transplantation.¹⁰⁷ Even so, it is clear that this discrimination against people with mental disabilities exists, at least on a case-by-case basis. For instance, Ellie Ward, a 3-year-old child with Down syndrome in Ohio, was denied a heart transplant because of her disability.¹⁰⁸ The parents of Lili Parra, an infant, were told that their daughter was taken off the heart transplant waiting list merely because she was *at risk* of having a developmental disability.¹⁰⁹

Among doctors and clinicians who hold the first opinion described above, the central concern is that that patients with mental disabilities will not be able to comply with complex postoperative care regimens. As a result of this view, “patients may be denied access to the [transplant] waiting list if their social supports are

deemed insufficient.”¹¹⁰ Other doctors believe that UNOS/OPTN should require organ transplant centers to submit data for patients with mental disabilities who do receive organ transplants so that UNOS/OPTN can evaluate how likely the patient’s cognitive impairment is to lead to “poor outcomes.”¹¹¹

In another article, three doctors warned that people with intellectual disabilities would seldom be suitable candidates for organ transplants, stating that the International Society for Heart and Lung Transplantation still listed intellectual disability as a relative contraindication to heart transplant.¹¹² The doctors stated that while patients with intellectual disabilities *could* be potential candidates for transplant, there was a need for a “two-pronged” psychosocial evaluation of both the patient and the patient’s caregivers, which would determine whether the patient had sufficient support to comply with postoperative care.¹¹³

Doctors with the second opinion described above, who believe that people with mental disabilities should never be excluded from an organ transplant on the basis of disability, have also argued that there is a need to remediate historical discrimination against specific groups of people with mental disabilities, such as people with psychiatric disabilities¹¹⁴ and people with I/DD.¹¹⁵ Dr. Aaron Wightman, a professor of bioethics at the University of Washington School of Medicine, and his colleagues produced several research articles specifically on this topic.¹¹⁶ Wightman’s articles and analyses generally argue or show that I/DD has limited

or almost no impact on the medical success of an organ transplant.¹¹⁷ Wightman additionally argues that people with I/DD should not be excluded from organ transplantation on the basis of what others assume about their social value, which he states is often the case when an organ transplant center excludes a person with I/DD based on the belief that they will have a lower quality of life than people without disabilities.¹¹⁸ Wightman does not provide examples of situations in which an organ transplant center has made such an exclusion. But some interviewees, such as Christine Rivera,¹¹⁹ report that such exclusions have indeed taken place.

With respect to postoperative care,

Wightman argues that even though people with I/DD (especially children with I/DD) may require significant supports to comply, “a societal failure to meet the needs of those

most vulnerable is not a reason to exclude them from receiving solid organ transplants.”¹²⁰ Similar arguments assessing postoperative care for people with psychiatric disabilities state that successful organ transplantation is possible when individuals receive sufficient support.¹²¹

Medical Success of Organ Transplants for People with Disabilities

NCD reviewed relevant clinical studies on the impact of intellectual and developmental disability, psychiatric disability, and HIV on the success of an organ transplant. These studies consistently find that transplant outcomes

These studies consistently find that transplant outcomes for people with disabilities are no worse than transplant outcomes for people without disabilities.

for people with disabilities are no worse than transplant outcomes for people without disabilities.¹²²

People with Intellectual and Developmental Disabilities (I/DD)

Research literature on transplant outcomes for people with I/DD refutes the concern that having an I/DD, in and of itself, has a significant negative impact on the medical success of an organ transplant. For instance, a 1998 study of kidney transplants found that the patient and graft survival rates for eight patients with I/DD after 7.5 years were “excellent.”¹²³ Similar outcomes exist for liver transplants, with a 2016 study finding that children with I/DD have comparable short-term graft and patient survival rates to children without intellectual disabilities, although they had more treatment-related hospitalizations than people without disabilities during the first year after transplant.¹²⁴

Heart transplantations into people with I/DD are particularly controversial. In fact, the International Society for Heart and Lung Transplants only removed “mental retardation” [sic] as a relative contraindication to heart transplantation in the 2016 revision of their official guidelines.¹²⁵ Nonetheless, studies find that that people with I/DD benefit significantly from heart transplants and that there are few justifications for denying them access.¹²⁶

The only concerns relating to the medical success of an organ transplant that may hold

some merit are those relating to some post-transplant outcomes for specific forms of I/DD. For example, since people with Down syndrome tend to have weaker immune systems, patients with Down syndrome may be at a higher risk for the development of cancer and infection after transplant than patients without Down syndrome.¹²⁷ Nevertheless, as described in Chapter 3, denying all patients with Down syndrome organ transplants on the basis of their disability ignores individual differences between patients and possible risk mitigation strategies, and discriminates on the basis of disability in violation of federal law.

People with Psychiatric Disabilities

There is no clear link between psychiatric disabilities and poor transplant outcomes.¹²⁸

In a 2017 literature review on outcomes for people with psychiatric disabilities receiving organ transplants, some studies found that the

presence of a specific psychiatric disability or its symptoms (such as a history of suicide attempts in a person with depression) increased post-transplant mortality rates or organ rejection, while other studies found that the impact of the same psychiatric disability was relatively limited.¹²⁹ Still other studies found that people with psychiatric disabilities who undergo organ transplantation do so very successfully with sufficient support, with at least one study determining that “psychiatric illnesses are not consistently associated with increased morbidity and mortality.”¹³⁰

The authors of this literature review noted that it was difficult to compare studies due to differences in sample size, study populations, and transplant selection criteria.¹³¹ But they concluded that “psychiatric patients are an extremely heterogeneous group” and the evidence did not support “barring patients . . . on the basis of their psychiatric illness alone.”¹³²

Patients Who Are HIV-Positive

Organ transplant centers are reluctant to perform organ transplants on patients with HIV and, as described in Chapter 3, sometimes have explicit policies listing the disorder as a contraindication to transplant.¹³³ In actuality, however, HIV-positive status does not significantly impact the likelihood of medical success. According to a 2002 paper arguing in favor of transplanting organs into people who are HIV-positive, “all published reports of transplantation in HIV-positive patients who are receiving multidrug antiretroviral regimens” reported that HIV-positive status did not impact the transplantation, nor did the immunosuppressive antibodies taken by transplant patients hasten the progression of their HIV.¹³⁴

Post-Operative Care for People with Disabilities Receiving Organ Transplants

The impact of disability on a patient’s ability to comply with post-operative care is complex because some disabilities, particularly psychiatric disabilities and I/DD, have characteristics that may cause patients difficulty following their post-transplant medication regimens unless they receive sufficient supports.¹³⁵ Patients with disabilities who receive proper supportive services that take into account their specific needs and disabilities, however, are perfectly

capable of following complex postoperative care regimens.¹³⁶

Geraldine Collins-Bride, a nurse practitioner at the University of California San Francisco, who was interviewed for this report, has provided counseling and support to several patients with I/DD who sought organ transplants. Collins-Bride said that, for transplant candidates with I/DD, both the person with I/DD and that person’s support system require intensive counseling reinforcing the importance of taking post-transplant medications consistently.¹³⁷ She indicated that developing prompts in the environment that remind the person with I/DD was important and suggested finding an action like eating dinner or a mechanism like a weekly pill container that may help the person remember when to take medication.¹³⁸

For additional information on what kinds of supports people with mental disabilities (especially people with I/DD) may need in order to successfully adhere to a postoperative care regimen, readers can consult the Autistic Self Advocacy Network (ASAN)’s guide for clinicians¹³⁹ as well as its *Guide to Supports Available to Organ Transplant Recipients with Disabilities*.¹⁴⁰

Ethical Issues and Bioethicist Perspectives on Organ Transplants for People with Disabilities

There are two primary ethical issues discussed by bioethicists and other stakeholders. The first is, “What is the proper relationship between disability and the allocation of organs?” The second is, “Is there a means of allocating scarce health care resources, such as organs, that does not discriminate on the basis of disability?”

Potential Methods of Allocating Organs

- “Greatest benefit”
- Donor/recipient match
- Medical necessity
- Sickest
- “First come, first serve”
- Randomized lottery system

Ethical Question 1: “What is the proper relationship between disability and the allocation of organs?”

Most legal theorists and philosophers agree that because organs are a scarce medical resource, some form of rationing must occur.¹⁴¹ As legal scholar David Orentlicher stated, “[i]nasmuch as we cannot avoid rationing, the question becomes how rationing should be implemented.”¹⁴²

Given that organs must be rationed, some bioethicists have argued that some aspects of disability, such as the impact of disability on quality of life, should be considered when a transplant center is attempting to determine who they should transplant.¹⁴³ They argue that disability may result in a lower quality of life, although not necessarily for all people with disabilities.¹⁴⁴

But there is no evidence that people with disabilities actually experience a lower quality of life than people without disabilities. People with disabilities tend to self-report that their quality

of life is the same as people without disabilities, regardless of the severity of their disability.¹⁴⁵ In fact, where people with disabilities do report that their disability has some impact on their quality of life, it is often related to architectural and societal barriers, as well as encountering the belief that disability inherently makes them less capable, rather than any inherent trait of the disability.¹⁴⁶

There is disagreement among stakeholders on what exactly “quality of life” is, how to measure it objectively, and whether disability actually reduces quality of life. Most means of attempting to objectively measure “quality of life,” such as Quality Adjusted Life Years (QALYs), may be based on assumptions about people with disabilities’ quality of life made

by people without disabilities and tend to limit the definition of the concept to aspects of physical, emotional, and cognitive functioning.¹⁴⁷ Disability Adjusted Life Years

(DALYs) are another means of attempting to objectively measure the impact of disability and/or health conditions on “quality of life.” DALYs add “the number of years of life lost” due to a certain disability “to the number of years lived with [that] disability” to determine the overall burden that disability places on a population (for instance, the overall burden of disability on the residents of a city).¹⁴⁸ Under the DALYs framework, the presumption is “that lifetime of [people with disabilities] is worth less than that of people without disabilities and that [people with disabilities] have fewer claims on health resources than do people without disabilities. The task is to find out how much less” through,

People with disabilities tend to self-report that their quality of life is the same as people without disabilities, regardless of the severity of their disability.

in part, “compar[ing] the value of extended life in people without disabilities with that in [people with disabilities].”¹⁴⁹

Bioethicist Arthur Caplan stated in his interview that the meaning of “quality of life” was clear and objective, and that it typically referred to mobility, the ability to perform self-care, and the ability to form relationships and interact with others. Caplan described the components of a person’s “quality of life,” therefore, as features of life that doctors in the field of rehabilitation can try to improve. Nonetheless, patients with “locked in syndrome”—disabilities that cause a person to lose complete physical control of their bodies and therefore access to some of what Caplan defines as critical to a good quality of life—report having the same quality of life as people without disabilities.¹⁵⁰

In many cases, therefore, when someone states that people with disabilities have a lower “quality of life,” this conclusion may not be based on an accurate assessment of the quality of life of people with disabilities. Bioethicist Julian Savulescu lists intellectual disability, infertility, and reduced opportunities for independent living and employment as characteristics of Down syndrome that “make . . . lives worse,” without examining social causes or whether people with these characteristics actually value their lives less.¹⁵¹ Bioethicist Joe Stramondo explains that this argument, known as “The Standard View,” is held by most people in the general population,¹⁵² which sees disability as inherently negative for all people that experience it.¹⁵³

The Standard View may result from excessive reliance on a deficit-based “medical model” of disability, which frames disabilities

as problematic illnesses or ailments to be cured.¹⁵⁴ The medical model tends to frame the disability itself as the “root cause” of disability-related disadvantages a person experiences, and assumes that the way to remedy those disadvantages is to cure the disability, rather than to address social prejudices or systematic barriers (for example, by offering services needed to increase opportunities for employment or to make independent living possible).¹⁵⁵ When a disability *cannot* be cured, therefore, overreliance on the medical model may lead people to assume that the person’s quality of life is automatically lower than that of a person without a disability.

These views also may be based on widespread beliefs that people with disabilities have less to contribute to society and therefore should receive lower priority for a scarce resource such as organs.¹⁵⁶ Such a view assumes that disability automatically reduces the contributions a person could make to society. Philosopher John Kilner states that such a view “robs people of any unconditional worth . . . and defines them purely in terms of their usefulness to others.”¹⁵⁷ This is also inconsistent with the widespread societal view in the United States that each individual is of equal worth.¹⁵⁸

Ethical Question 2: “Is there a means of allocating scarce healthcare resources, such as organs, that does not discriminate against people with disabilities?”

NCD’s review of relevant ethical and medical literature found no clear answer to this question. Some people feel that scarce medical resources should be allocated based on *who*

would receive the greatest benefit from the resource.¹⁵⁹ Note, however, that the meaning of the phrase “greatest benefit” may be ambiguous. The “greatest benefit” could refer to the greatest improvements in “quality of life” from receiving the resource.¹⁶⁰ But as noted under “Ethical Question 1,” many methods of measuring “quality of life” and how much it is improved by treating a person—such as QALYs—discriminate against people with disabilities.

Although they may use different definitions of “greatest benefit,” bioethicists often consider how a person will benefit from an organ transplant in considering how to allocate such a scarce resource. For

example, bioethicist Arthur Caplan has argued that “severely intellectually impaired” children and people “who are almost in a coma” should not be considered for organ transplants and that

60-year-old individuals should be prioritized lower than 20-year-old individuals because in his view, the 20-year-old individuals would benefit from the organ for longer.¹⁶¹ In other words, he believes that organs should be allocated where they will prolong lives for the longest time.¹⁶² Caplan nonetheless noted the underrepresentation of women, older people, people of color, and people with disabilities among organ transplant recipients and feels that this underrepresentation may raise concerns of equity.¹⁶³ This reflects the concern of other bioethicists who worry that factors

such as socioeconomic status and race have an impact on perceived “quality of life” and the degree to which a person benefits from an organ transplant.¹⁶⁴

Ethicists and stakeholders disagree as to whether it is unjust to prioritize people expected to live longer after a particular organ transplant over people whose co-occurring disabilities, conditions, or age may shorten their lifespan.¹⁶⁵ For instance, as discussed in Chapter 2, some disabilities or chronic illnesses, such as Down syndrome, may reduce a person’s life expectancy due to co-occurring conditions such as a compromised immune system, leading to these people

receiving lower priority for a transplant even independent of presumptions about their quality of life.¹⁶⁶ But as John Kilner reported in a study of 453 United States medical directors of renal dialysis and

transplant centers, these people view the degree of “medical benefit” a person will receive from a transplant as important.¹⁶⁷

In an interview for this report series, bioethicist Joe Stramondo contemplated how he would allocate a scarce resource such as organs:

Basing [organ allocation] on [life expectancy] would build in a disadvantage to certain groups of people. Maybe there should be a thing where there’s a floor beneath which I wouldn’t want to drop. Maybe it should

Ethicists and stakeholders disagree as to whether it is unjust to prioritize people expected to live longer after a particular organ transplant over people whose co-occurring disabilities, conditions, or age may shorten their lifespan.

be 5 years. Where we go, “Anybody that can live 5 years with the organ ought to have an equal shot at the treatment and [be] entered into the lottery.” I do have an intuition that if there’s a heart, and the person won’t survive, they shouldn’t get the heart. It should go to the person who will live 5, 10, or 15 years with that heart and not the person who will only live 6 months.

Bioethicist John Harris disagrees, arguing that allocating scarce resources on the basis of how long the treatment will extend the patient’s life is ageist and discounts the intrinsic value of a person’s life to them, regardless of how long they have left to

live.¹⁶⁸ This view is more in line with the views of most individuals NCD interviewed for this report. Mrs. Rivera, the mother of Amelia Rivera, argued

that the allocation of scarce resources should only be based on whether someone is medically capable of receiving a transplant. Marty Ford, a representative of The Arc, a nonprofit organization that serves people with developmental disabilities, felt that organ transplant decisions should strictly be based on whether there was a match between the donated organ and the recipient. Ms. Collins-Bride, the nurse practitioner, argued that the “medical necessity” of the transplant should be considered above all else.

UNOS/OPTN’s current methods for allocating donated organs prioritize the sickest patients

first and those who have been on the waiting list the longest, according to a “first come, first served” policy.¹⁶⁹ Additionally, UNOS/OPTN’s computer system automatically screens out incompatible candidates for transplant when creating the waiting list to determine allocation of a donor organ.¹⁷⁰ As explained in Chapter 1, UNOS/OPTN’s guidelines and point system are specific to each organ, but the guidelines are not disability-specific, focusing instead on specific medical aspects of transplanting each organ.

Organs could alternatively be allocated using a method that is completely randomized, bearing no relationship to either health or quality of life, such as a lottery system.¹⁷¹ While lotteries

are fundamentally nondiscriminatory (since they do not value people with disabilities over people without disabilities), the use of lotteries alone would create unjust results.¹⁷²

UNOS/OPTN’s current methods for allocating donated organs prioritize the sickest patients first and those who have been on the waiting list the longest.

For instance, they might result in organs going to people who only just got onto the organ transplant waiting list, which may not be equitable because it may mean that a less sick person will be prioritized above a much sicker person. According to ethicist Govind Persad, use of a lottery alone would also fail to consider medical factors relevant to the transplant, such as how long someone can be expected to live after that transplant.¹⁷³ He argues it might be unethical to prioritize someone who would live only 4 months after transplant (for medical reasons) over someone who might live for 40 years after transplant.¹⁷⁴

Finally, organs could be allocated using a “first come first serve” system,” in which whoever managed to get onto the waiting list first would receive the organ.¹⁷⁵ But this would likely mean that people with more knowledge of how the transplant system works would come out ahead of less-informed people.¹⁷⁶ Persad argues that the people best positioned to benefit from a purely “first come first serve” system are the wealthy, those who can travel to a transplant center more quickly, and those who have no additional responsibilities such as employment requiring them to be in a specific place at a specific time or childcare concerns.¹⁷⁷ A “first come first serve system” alone would also disadvantage many people with disabilities, who may have more difficulty travelling to a transplant center due to accessibility issues, or more difficulty navigating complex bureaucratic systems due to cognitive or other limitations.

Existing Medical and Ethical Guidelines for Organ Transplants

UNOS’s Ethics Committee, under the guidance of the US Department of Health and Human Services, has created a set of nonbinding ethical allocation principles titled “Ethical Principles in the Allocation of Human Organs.”¹⁷⁸ The American Medical Association has similarly created a nonbinding “Code of Medical Ethics” on organ transplantation.¹⁷⁹ The degree to which either set of guidelines is followed by organ

transplant centers or OPOs is unknown, as NCD found no sources describing the extent to which organ transplant center policies comport with the guidelines. In other contexts, such as determination of brain death, the level of adherence to guidelines varies widely among hospitals¹⁸⁰ and it seems unlikely, given the variety in transplant policies among hospitals, that adherence in the organ transplant context is much different.

Nevertheless, this guidance by UNOS

UNOS’s guidelines state that allocation systems should exclude considerations of the social worth of individuals, and that they should “rule out excluding individual members of a social group or giving them low priority simply because the group has statistically poorer outcomes.”

itself, as well as that from the American Medical Association, may influence how organ transplant and procurement centers allocate organs. UNOS’s guidelines state that allocation systems should exclude considerations of the social worth of individuals, and that they should “rule out

excluding individual members of a social group or giving them low priority simply because the group has statistically poorer outcomes.”¹⁸¹

But the guidelines also state that “[f]actors relevant to access to the transplant waiting list, as distinguished from medical criteria used in the equitable allocation of organs . . . include psychosocial factors (e.g., financial and social support, patient adherence).”¹⁸² Allowing organ transplant centers to consider the financial and social support available to the patient when determining who will end up on the transplant waiting list undermines UNOS’s claims that members of certain social groups should not

be ruled out just because those groups have statistically poorer outcomes.

The American Medical Association's Code of Medical Ethics states that physicians should ensure "organs for transplantation are allocated to recipients on the basis of ethically sound criteria, including but not limited to likelihood of benefit, urgency of need, change in quality of life, duration of benefit, and, in certain cases, amount of resources required for successful treatment."¹⁸³ As stated above, ethicists disagree on the degree and the manner to which likelihood of benefit should influence organ allocation decisions. Additionally, the American Medical Association's Code of Medical Ethics argues that transplant physicians and OPOs should study whether the benefits of financial incentives for organ donation outweigh the potential ethical issues (such as the voluntariness of the donation

or a reduction in the number of altruistic organ donations).¹⁸⁴ These statements rightly consider the possibility of coercive organ donations and may make the exploitation of people with newly acquired injuries less likely (as described in Chapter 1).

The ethical considerations involved in this subject are complex, are the subject of much debate, and have not been resolved. While NCD does not at this time take a position on this ethical debate, two things are clear. First, organs must be allocated under a system that prevents discrimination on the basis of disability. Second, that allocation system should avoid criteria, such as QALYS, that tend to screen out people with disabilities by necessarily finding that people with disabilities will not receive the same medical benefit from organ transplants as people without disabilities.

Chapter 3: Federal Laws, Regulations, and Guidance and Their Impact on Organ Transplants for People with Disabilities

The Americans with Disabilities Act

The Americans with Disabilities Act (ADA) prohibits discrimination on the basis of disability in the organ transplantation process. Public hospitals and transplant centers are covered by Title II of the ADA, which provides that any “public entity,” including “any department, agency . . . or other instrumentality of a State or States or local government,”¹⁸⁵ is prohibited from discriminating against an individual with a disability on the basis of that disability.¹⁸⁶ Public entities are likewise prohibited from excluding qualified individuals from participation in or denying them the benefits of the services, programs, or activities of a public entity on the basis of their disability.¹⁸⁷

Privately operated healthcare establishments, including hospitals and transplant centers, are also typically covered by the ADA because they are “public accommodations” under Title III.¹⁸⁸ Privately operated healthcare establishments, with the exception of some religiously operated healthcare systems and facilities,¹⁸⁹ are precluded from “the imposition or application of eligibility criteria that screen out or tend to screen out

an individual with a disability or any class of individuals with disabilities from fully and equally enjoying any goods, services, facilities, privileges, advantages, or accommodations.”¹⁹⁰ Eligibility criteria that discriminate based on disability may be used only when such criteria are “necessary for the provision of the goods, services, facilities, privileges, advantages, or accommodations being offered.”¹⁹¹

The ADA requires that organ transplant centers make reasonable modifications to their policies, practices, and procedures to ensure equal opportunity for people with disabilities.¹⁹² Modifications must be made unless they would cause a fundamental alteration of the transplant center’s services.¹⁹³ Reasonable modifications must be considered on an individualized, case-by-case basis, rather than through generalized decision making, in order to level the playing field for people with disabilities.¹⁹⁴

Because the ADA requires individualized consideration of disability, it requires an individualized assessment of every person with a disability seeking an organ transplant.¹⁹⁵ The ADA seeks to eliminate “barriers caused by the use

Because the ADA requires individualized consideration of disability, it requires an individualized assessment of every person with a disability seeking an organ transplant.

of stereotypical assumptions that are ‘not truly indicative of the individual ability of [individuals with disabilities] to participate in, and contribute to, society.’”¹⁹⁶ Decisions concerning organ allocation therefore cannot be based on blanket assumptions regarding a person’s disability.¹⁹⁷ This includes unfounded assumptions that a person’s disability may make him or her less able to comply with postoperative requirements, or that having a disability lowers the quality or value of a person’s life.¹⁹⁸ In other words, physicians must weigh the medical status of each individual patient and that patient’s ability to comply with postoperative requirements while also making reasonable modifications to their policies and practices, including assisting people to secure additional support services that may be needed.¹⁹⁹

Reasonable modifications in this context may include the provision of a variety of supports or services.

Geraldine Collins-Bride, a nurse practitioner who was interviewed by NCD for this report, stated that important modifications may include a consultation with an individual seeking transplant and that person’s family or other support network to determine who will assist the individual post-transplant.²⁰⁰ Additional modifications include identifying any prompts that may help the individual adhere to the post-transplant medication schedule and frequent post-operative follow-up with the patient, as discussed in Chapter 2.²⁰¹ Reasonable modifications may also require referrals to social workers and state and community agencies so patients can

obtain support services,²⁰² as discussed above, including a home health aide, visiting nurse, or personal care attendant, or the utilization of supported decision making. Because the ADA’s reasonable modifications mandate is broad, it may be interpreted to require that a transplant center assist an individual with a disability seeking a transplant in securing these services and may even require the transplant center to pay for such services under certain circumstances, and to the extent that the cost is reasonable.²⁰³

Section 504 of the Rehabilitation Act of 1973

Because most hospitals, transplant centers, and other healthcare facilities are recipients of Medicare and Medicaid funds, or federal subsidies under the Affordable Care Act, they are subject to Section 504’s antidiscrimination provision.

Section 504 prohibits discrimination against people with disabilities in programs or activities receiving federal funding, and imposes virtually the same obligations as the ADA does.²⁰⁴ Section 504 applies not only to healthcare organizations

that are instrumentalities of the state or local government, but also to “an entire corporation, partnership, or other private organization, or an entire sole proprietorship . . . which is principally engaged in the business of providing . . . health care.”²⁰⁵ Because most hospitals, transplant centers, and other healthcare facilities are recipients of Medicare and Medicaid funds, or federal subsidies under the Affordable Care Act, they are subject to Section 504’s antidiscrimination provision,²⁰⁶ which extends to “all the operations of” a program or activity, “any part of which is extended Federal financial assistance.”²⁰⁷

Section 1557 of the Patient Protection and Affordable Care Act

Section 1557 is the nondiscrimination provision of the Affordable Care Act, and prohibits discrimination on the basis of race, color, national origin, sex, age, or disability in certain health programs or activities, including any health program that receives funding from HHS or that HHS administers.²⁰⁸ Section 1557 therefore applies to UNOS/OPTN. Section 1557 may also apply to organ transplant centers to the extent that those transplant centers receive federal financial assistance from HHS.²⁰⁹

HHS's UNOS Guidelines

The Federal Government must also comply with Section 504 in its own programs and activities concerning organ transplantation, including OPTN and UNOS.²¹⁰

While nothing in UNOS's organ transplant guidelines is inconsistent with the ADA, the guidelines do not explicitly state how disability should be considered within the context of organ transplantation.²¹¹ Instead, the UNOS organ transplant guidelines provide only that the allocation of organs should be based on "sound medical judgment," "promote patient access to transplantation," and that the "criteria for determining suitable transplant candidates" should be "expressed, to the extent possible, through objective and measurable medical criteria."²¹² These guidelines arguably support the individualized assessment required by the ADA, and do not appear to discriminate on the

basis of disability. Consistent with the ADA's nondiscrimination requirements, the UNOS/OPTN Ethics Committee has taken the position that "patients with disabilities should not be excluded from consideration for transplant solely by virtue of their disability."²¹³

Under both the ADA and Section 504, as well as the UNOS guidelines, therefore, an individual may not be excluded from an organ transplant waiting list solely because of a disability, or because of generalized assumptions surrounding a disability. But as discussed in the section below, disability-based discrimination has continued despite the ADA, Section 504, and UNOS guidelines.

Section 1557 therefore applies to UNOS/OPTN. Section 1557 may also apply to organ transplant centers to the extent that those transplant centers receive federal financial assistance from HHS.

Case Law and Guidance Regarding Organ Transplantation and Federal Law

NCD is unaware of any published federal or state court decisions

addressing disability discrimination under federal law in the organ transplantation context. Over the years, however, both the Department of Health and Human Services' (HHS) Office for Civil Rights (OCR) and the Department of Justice (DOJ) Civil Rights Division, have addressed a number of complaints alleging discrimination on the basis of disability and have provided technical assistance to covered entities to help ensure compliance with their legal responsibilities under federal civil rights laws. Most recently, OCR is providing technical assistance to the University of North Carolina Health Care system (UNC) in the ongoing development of its transplant eligibility policy

after working with UNC to ensure an individual with an intellectual disability was deemed eligible to be considered for placement on the transplant waiting list. In its press release, OCR noted that excluding people from access to organ transplants on the basis of “stereotypes about persons with disabilities” is against the law.²¹⁴

The lack of court decisions and limited agency decisions addressing discrimination against people with disabilities in the organ transplant process likely reflects the following factors that will be explored in this section: (1) the length of time it takes to pursue discrimination claims under federal law; (2) the fact that people with disabilities who are denied organ transplants may not realize that they have been subjected to illegal discrimination; and (3) the lack of federal guidance in this area.

First, the absence of case law concerning discrimination for organ transplants is likely tied to the length of time it takes to pursue a claim under federal law, where court proceedings can often take months or even years. Moreover, it is not hard to imagine why individuals dealing with life-threatening conditions might avoid the challenges of pursuing litigation.²¹⁵ This is precisely what happened to Lief O’Neill, a high schooler with autism who was initially denied a heart transplant in Oregon and who eventually received one in California.²¹⁶ As his mother described in her testimony regarding the importance of enacting a state law in Oregon to supplement federal law, Lief was far too ill to pursue a federal claim challenging

the discriminatory nature of the denial of his transplant.²¹⁷

Second, people with disabilities who are denied organ transplants may not realize that they have been subjected to illegal discrimination. Misty Cargill, a woman with an intellectual disability, was denied a kidney transplant in a letter that was only 39 words long and made no reference to any of the factors related to her denial.²¹⁸ If her caseworker had not called the hospital to inquire further, she may never have known that there were even discriminatory motives at play in the decision, and that the hospital had decided on the basis of her disability alone that she did not have the mental competency to make an informed

decision to choose a transplant.²¹⁹ This hidden discrimination in the organ transplantation process can also be difficult to address in a legal challenge where it extends beyond the

denial of a transplant itself, as when Lief O’Neill was not informed that an LVAD could extend his life while he waited for a transplant because of his disability.²²⁰

In other situations, and as described in Chapter 1, the informal manner in which organ transplant eligibility decisions are often made makes it difficult to determine whether discrimination occurred.²²¹ The inconsistent standards and varying informal policies that different organ transplant centers apply when evaluating people with disabilities only make this discrimination harder to notice, let alone to legally challenge.²²² Medical providers themselves also may be unaware of the ways in

[T]he informal manner in which organ transplant eligibility decisions are often made makes it difficult to determine whether discrimination occurred.

which civil rights laws prohibit discrimination on the basis of disability when determining eligibility for organ transplantation. Transplant teams “[a]cting under their own perceived subjective clinical judgment in complicated medical scenarios” may not even be aware that civil rights laws apply.²²³

Finally, the lack of federal guidance concerning the civil rights laws that apply to the organ transplantation process may contribute to the absence of cases in this process. DOJ has authority to interpret and enforce Titles II²²⁴ and III²²⁵ of the ADA,²²⁶ Under Executive Order 12250, DOJ is also authorized to coordinate the consistent implementation of Section 504 of the Rehabilitation Act (Section 504) across the Federal Government.

HHS has the authority to investigate complaints related to “the provision of health care and social services” under Title II of the ADA.²²⁷ HHS also has authority to promulgate regulations, issue technical assistance and guidance, and enforce the obligations of Section 504 with respect to entities receiving federal funding from HHS and HHS programs and activities.²²⁸ Finally, HHS has authority under Section 1557 of the Affordable Care Act (Section 1557) to promulgate regulations, issue technical assistance and guidance, and enforce obligations with respect to health programs and activities that receive federal funding from HHS as well as programs or activities administered by HHS under Title I of the Affordable Care Act (Title I) and any program or activity administered by any entity established under Title I.²²⁹ The ADA applies to organ transplant centers and hospitals.

Section 504 and Section 1557 also apply to organ transplant centers and hospitals that receive funding from HHS and programs conducted by the federal government, including its involvement in the organ transplantation process. But there is no specific guidance as of the date of this report from DOJ or HHS describing what the ADA, Section 504, or Section 1557 require with respect to people with disabilities seeking organ transplants. The February 2019 news release about the complaint resolved by HHS is the most recent example of the agency’s application of civil rights protections in the organ transplant process.

Some have theorized that there are no cases applying federal law to disability discrimination in the organ transplant context due to “the

accepted discretion allowed to physicians”²³⁰ or the reluctance of courts to apply the ADA and its reasonable modification mandate to health care.²³¹ This argument is unfounded,

and the Supreme Court has made clear that the ADA applies to medical decision making.²³² The argument stems from old cases brought under Section 504, largely prior to passage of the ADA, such as the 1980s “*Baby Doe* cases” about newborns with disabilities²³³ and *In re Baby K*.²³⁴ In those cases, courts were attempting to address the allocation of scarce healthcare resources.²³⁵

For instance, in *United States v. University Hospital*, one of the leading *Baby Doe* cases, a Second Circuit panel’s decision rested in part on acceptance of the argument that Section 504 only prohibits discrimination “where the individual’s handicap [sic] is unrelated to, and

[T]he lack of federal guidance concerning the civil rights laws that apply to the organ transplantation process may contribute to the absence of cases in this process.



thus improper to consideration of, the services in question.”²³⁶ The court went on to find that discrimination is consequently warranted in the medical context because “where medical treatment is at issue, it is typically the handicap [sic] itself that gives rise to, or at least contributes to, the need for services.”²³⁷ The dissent saw it differently, emphasizing that Section 504 was patterned after other civil rights laws and “constitutes the establishment of a broad government policy that programs receiving federal financial assistance shall be operated without discrimination on the basis of handicap [sic].”²³⁸ The government’s aim in preventing discrimination on the basis of disability, according to the dissent, was not to “override a medical judgment” but rather to determine “whether

a judgment in question is a *bona fide* medical judgment.”²³⁹

The court in *In re Baby K* did override the decision-making authority of physicians. The physicians in *In re Baby K* were opposed to providing care that had “no therapeutic or palliative purpose [and was thus] medically unnecessary and inappropriate” to Baby K, a baby born with anencephaly, a condition where a child is born without portions of the brain and skull.²⁴⁰ The hospital consequently wanted to be excused from any obligation to provide emergency care under the Emergency Medical Treatment and Active Labor Act (EMTALA), Section 504, and the ADA.²⁴¹

The court rejected the hospital’s arguments.²⁴² The Fourth Circuit, on appeal, recognized the

difficulty in scrutinizing medical decision making but affirmed the judgment, explaining that “[w]e recognize the dilemma facing physicians who are requested to provide treatment they consider morally and ethically inappropriate, but we cannot ignore the plain language of the statute because to do so would transcend our judicial function.”²⁴³

Even if the *Baby Doe* and *In re Baby K* cases could be understood to create any ambiguity about the applicability of disability discrimination laws to the organ transplant process, any doubt was erased by the Supreme Court’s 1998 landmark ruling in *Bragdon v. Abbott*, which held that the ADA applies to medical decision making.²⁴⁴ In *Bragdon*, the Court found that HIV is a disability under the ADA, that the plaintiff was therefore protected from denial of treatment on the basis of his disability, and that the plaintiff must be afforded reasonable modifications to practices and procedures in order to receive that treatment.²⁴⁵ The Court further held that while a treating physician has the right to determine whether a treatment or accommodation is unreasonable, such an “assessment must be based on medical or other objective evidence” and not on the physician’s belief alone.²⁴⁶ As the Court elaborated, the belief of a medical professional, “even if maintained in good faith,” warrants “no special deference,” and a medical professional who denies treatment or accommodation to a person with a disability is therefore liable under the ADA unless the decision can be determined to be “reasonable in light of the available medical evidence.”²⁴⁷

Other courts have reached similar conclusions, such as the Delaware District Court in 1993,

holding that decisions regarding refusal of treatment must be based on “medical reasons” and that a hospital may be held liable if it is aware of the discriminatory basis for the refusal and does not intervene.²⁴⁸ Even the *Baby K* court—which did override the decision making of physicians—applied Section 504 and the ADA, as well as the EMTALA in holding that Baby K must receive treatment.²⁴⁹

A DOJ regulation likewise concludes that the ADA is applicable to medical decision making, and states that a provider may only refer patients to another facility for treatment when the treatment sought is not within the provider’s specialty and “the referring provider would make a similar referral for an individual without a disability who seeks or requires the same

treatment or services.”²⁵⁰

A 1998 settlement agreement between DOJ and George Washington University (GWU) Medical Center regarding

the denial of treatment to a patient with HIV also clarified that disability should not be factored into medical decision making. Under the agreement, GWU Hospital was required to issue a policy stating that, “medically appropriate treatment (as determined by reasonable medical judgment based on current medical knowledge) shall not be denied or withheld on the basis of the patient’s infectious disease status.”²⁵¹

Do Organ Transplant Centers Follow Federal Law?

The extent to which organ transplant centers follow federal disability nondiscrimination laws by providing reasonable modifications to people with disabilities and otherwise avoiding

disability-based discrimination in organ allocation decisions is difficult to track, particularly given that discrimination against people with disabilities often occurs informally.²⁵² That said, as described below, it is apparent that some organ transplant centers do not comply with the antidiscrimination requirements of the ADA and Section 504 when considering transplant candidates with disabilities.

As examined in detail in Chapters 1 and 2, many organ transplant centers may view certain disabilities as absolute or relative contraindications to organ transplants, or be unaware that the medical outcomes of organ transplants for people with disabilities are no worse than those for people without disabilities.

These biases among medical professionals make it unlikely that all providers are following federal law by conducting individualized assessments of the impact of transplant candidates' disabilities

or considering reasonable modifications and supports available to each person in making determinations about what patients should be placed on the waitlist for an organ transplant.

This existence of an underlying bias against people with disabilities is apparent on the websites of many organ transplant centers, even in states with their own antidiscrimination laws.²⁵³ St. Joseph Hospital in California lists transplant eligibility criteria that are in plain conflict with federal and California law, stating that “[k]idney transplantation is usually not recommended for patients who have . . . [i]mmune deficiency disease [or] [p]sychosocial conditions or situations that interfere with post-

transplant care or medication management.”²⁵⁴

The University of Pennsylvania’s Penn Medicine states that its lung transplant program “does not list or transplant patients who have . . . HIV/AIDS, [d]ocumented history of repeated medical non-compliance, [or] [s]evere and on-going psychiatric problems that interfere with self-care.”²⁵⁵ Its kidney program similarly lists “active and unstable psychiatric illness” among its absolute contraindications to transplant.²⁵⁶ The University of Pittsburgh Medical Center does not even allow evaluation for liver transplant until the person seeking evaluation is “free of . . . [d]isabling psychiatric conditions and [d]ocumented medical non-compliance.”²⁵⁷

While some organ transplant centers do not specifically mention psychiatric or developmental disabilities as relative or absolute contraindications to transplants, they list medical noncompliance

among the contraindications to transplant, and do not indicate that the transplant center will consider—as required by federal law—any supports that the patient has or is eligible to receive.²⁵⁸ For instance, New Jersey’s Barnabus Health lists “[s]evere psychiatric illness, uncontrolled with medication” and prior chronic noncompliance with medication or treatment regimens as not just relative, but absolute contraindications to kidney transplant.²⁵⁹

In other cases, whether organ transplant centers discriminate may be difficult to discern from the face of their policies. For example, Stanford University’s evaluation criteria for older adults consider an “inability to care for oneself

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without assistance” as a relative contraindication for an organ transplant.²⁶⁰ Unless Stanford also weighs the supports available to the individual when making determinations about organ transplants, this policy of denying transplants to older adults who cannot care for themselves independently arguably violates the ADA and California’s own antidiscrimination law.²⁶¹

Transplant centers in New York have similarly problematic guidelines for the evaluation of transplant candidates. For instance, Columbia University’s Center for Advanced Lung Disease and Transplantation states that individuals should have a “[h]istory of compliance with follow-up visits and medications” and “[n]o significant and active psychiatric problems.”²⁶²

In Florida, the University of Florida Health’s transplant center lists discriminatory criteria as not only relative, but absolute contraindications for transplants, stating that patients must have “[c]apacity to perform daily activities without assistance . . . [and p]sychosocial health in good standing” in order to receive a kidney transplant.²⁶³ Tampa General Hospital lists “AIDS or HIV-positive diagnosis, [m]ental illness, including schizophrenia and psychosis . . . [and a] history of noncompliance for medical appointments, medical advice, and/or medical regimens” among contraindications that “can preclude” the hospital from listing someone for a liver transplant.²⁶⁴ The hospital has similar contraindications for kidney transplant.²⁶⁵ Several

other states,²⁶⁶ including Arizona, Colorado, Kentucky, and South Carolina have transplant centers that list medical noncompliance,²⁶⁷ HIV,²⁶⁸ and/or a history of, as opposed to current, substance use disorder²⁶⁹ among their relative contraindications to transplant.

The resolution of the recent complaint filed with OCR against UNC Health Care, discussed in the previous section, further demonstrates that organ transplant centers sometimes fail to adhere to federal law.²⁷⁰ Disability advocates have also found that organ transplant centers

may ignore federal law unless and until their conduct is challenged. For example, prior to the debate in Maryland surrounding proposed antidiscrimination legislation (which became law in 2015), the organ transplantation eligibility policies of the University of Maryland Medical

In Florida, the University of Florida Health’s transplant center lists discriminatory criteria as not only relative, but absolute contraindications for transplants, stating that patients must have “[c]apacity to perform daily activities without assistance . . . [and p]sychosocial health in good standing” in order to receive a kidney transplant.

Center’s (UMMC) transplant center listed “severe psychiatric disease, severe mental retardation [sic], and unresolvable psychosocial problems” as “absolute contraindications for renal transplants.”²⁷¹ UMMC removed “severe mental retardation” [sic] from these guidelines after advocates raised the possibility that they were violating the law, but kept “severe psychiatric disease” and “unresolvable psychosocial problems” listed as absolute contraindications to transplant.²⁷² None of those guidelines are currently on the transplant program’s website.²⁷³

Chapter 4: State Laws Prohibiting Discrimination Against People with Disabilities in Organ Transplants

A Brief Overview of State Laws

Nine states have enacted legislation banning organ transplant discrimination and two states—New York²⁷⁴ and Washington²⁷⁵—are considering such a ban and have legislation pending. The nine states that have passed a law banning organ transplant discrimination are California, New Jersey, Maryland, Massachusetts, Oregon, Delaware, Ohio, Kansas, and Pennsylvania. While California was the first state to enact such a law in 1996, the majority of state laws have been enacted within the last six years. No published cases have applied these laws, likely due both to the reasons set forth in Chapter 2 explaining the absence of federal case law, and because the majority of these laws are very recent. This chapter provides an overview of these laws before examining the oldest state law in California, and one of the newer laws in Maryland.

California’s Uniform Anatomical Gift Act was revised in 1996 to prohibit discrimination on the basis of disability.²⁷⁶ Under California’s law, eligibility for a transplant cannot be determined on the basis of the patient’s disability, except in instances where the disability is “medically significant” to the success of the transplant.²⁷⁷ The patient also cannot be required to be

States with Organ Transplant Antidiscrimination Laws

- California
- Delaware
- Kansas
- Maryland
- Massachusetts
- New Jersey
- Ohio
- Oregon
- Pennsylvania

able to live independently as a condition of the transplant provided that the patient has an adequate support system to ensure postoperative needs are met.²⁷⁸ The act also provides for priority review, meaning that courts place cases on a fast track calendar to resolve disputes quickly.²⁷⁹ The law applies to every part of the organ transplant process involving physician or transplant team discretion, including referrals, evaluation, and placement on the transplant waiting list.²⁸⁰ California’s statute is discussed in more detail in the section, “California’s Organ Transplant Nondiscrimination Law,” below.

New Jersey passed its antidiscrimination law in 2013²⁸¹ in response to the case of Amelia Rivera, a young girl who was denied a

kidney transplant when she was 3 years old because she has Wolf-Hirschhorn syndrome, a genetic condition that can cause physical and mental disabilities.²⁸² The legislation “follow[ed] California’s approach” in several ways.²⁸³ As in the California statute, the ability to live independently is not a requirement for transplant, and priority review is provided to resolve disputes.²⁸⁴

Unlike New Jersey and California before it, Maryland did not enact its 2015 antidiscrimination law²⁸⁵ in response to a specific case of discrimination against an individual with a disability.²⁸⁶ Instead, Maryland worked with a coalition of advocacy organizations and used model legislation drafted by ASAN as a basis for its law.²⁸⁷ Maryland’s statute is discussed in more detail in the section, “Maryland’s Organ Transplant Nondiscrimination Law.”

Passed in 2016, Massachusetts’ antidiscrimination bill²⁸⁸ allows the state’s attorney general to take civil action against violators of the statute and imposes fines of up to \$50,000 for the first violation and \$100,000 for subsequent violations.²⁸⁹ As in Maryland, the law was not a reaction to an instance of discrimination against a particular person.²⁹⁰

In 2017, Oregon’s state legislature unanimously approved House Bill 2839,²⁹¹ which prohibits discrimination in organ transplants on the basis of disability, except where the disability would make the transplant unlikely to succeed.²⁹² Advocates and providers alike supported the bill, which not only prohibited discrimination on the basis of disability and provided priority review to resolve disputes, but “[clarified] official state policy for hospitals and transplant centers” by emphasizing the obligation to follow the law.²⁹³ Oregon’s bill also provided detail regarding the equitable relief that can be sought, including “auxiliary aids and

services,” “the modification of a policy, practice or procedure of a covered entity,” and making facilities “readily accessible to and usable by a qualified individual with a disability.”²⁹⁴

In 2017, Delaware passed a law prohibiting discrimination in the organ transplant process on the basis of a person’s disability unless it is “medically significant” to the success of the transplant, as determined following an individualized assessment by a physician.²⁹⁵ As with other similar state laws, the ability to comply with postoperative requirements is not disqualifying if an “individual has the necessary support system to assist the individual in complying with post-transplant medical requirements.”²⁹⁶ The law also echoes the ADA, requiring entities to “make reasonable modifications in policies, practices, or procedures, when such modifications are necessary” for patients with disabilities to access needed services.²⁹⁷

In 2018, Kansas²⁹⁸ and Ohio²⁹⁹ both passed similar nondiscrimination laws. Recently, and after years of debate, Pennsylvania did likewise.³⁰⁰ John Sarbatina, a Pennsylvania state senator, first introduced “Paul’s Law” in 2014, named after Paul Corby, a man with autism who was denied a heart transplant.³⁰¹ The law, like those that passed in other states, seeks to prohibit discrimination on the basis of disability, and prevent individuals with ““an adequate support system”” from being denied transplants due to an inability to comply with postoperative regimens.³⁰² Note, however, that Pennsylvania’s bill lacks the detail of many of its predecessors. The bill provides only that discrimination solely on the basis of disability is prohibited, and that unless “following an individualized evaluation” a disability is deemed to be “medically

significant,” individuals who have a “necessary support system” should not be rejected for an inability to comply with the postoperative regimen.³⁰³

Particularly for the states that have only recently enacted laws to prevent discrimination against people with disabilities in the organ transplant process, it is difficult to know how the laws are being applied in practice. But as discussed in Chapter 3, several transplant centers have information listed on their websites that indicate they are not in compliance with the antidiscrimination laws in their state, particularly when it comes to the treatment of people with psychiatric disabilities and evaluating individuals’ ability to comply with the postoperative regimen. This may be due to a lack of knowledge about the state law, or a lack of understanding regarding the breadth of disabilities the state law was meant to protect. For instance, California and New Jersey—the first two states to enact antidiscrimination legislation, and the two states most often invoked by states pursuing similar laws—enacted their legislation specifically to protect people with developmental disabilities in the organ transplant context.³⁰⁴ As a result, some physicians and organ transplant centers may not be aware that legal protections also extend to other types of disabilities.

California’s Organ Transplant Nondiscrimination Law

California’s law banning organ transplant discrimination is the oldest in the country and has been used as a model for subsequent laws in other states.³⁰⁵ The law came about as a response to the battle of Sandra Jensen, a woman with Down syndrome, to obtain a heart transplant that was needed to save her life.³⁰⁶

Ms. Jensen had been denied a transplant by both Stanford University and the University of California at San Diego for over 2 years, despite the fact that there was no evidence indicating that her disability lessened the likelihood of the transplant being successful.³⁰⁷ Disability Rights California and other advocates argued that Ms. Jensen’s civil rights were violated when she was denied the chance to receive an organ transplant because of her disability.³⁰⁸ Ms. Jensen eventually received a heart transplant at Stanford University, becoming the first person with Down syndrome to receive a major transplant,³⁰⁹ and Disability Rights California later led the fight to pass California’s 1996 law prohibiting discrimination in organ transplantation, in order to prevent what happened to Ms. Jensen from happening to other people with disabilities.³¹⁰

The Uniform Anatomical Gift Act prohibits denying a transplant due solely to a patient’s disability, using the definition of disability under the ADA.³¹¹ The law “does permit denying eligibility for transplant ‘to the extent that the physical or mental disability has been found by a physician and surgeon, following a case-by-case evaluation of the potential recipient, to be medically significant to the provision of the anatomical gift.’”³¹² This caveat in the Uniform Anatomical Gift Act consequently provides significant leeway for bias to persist in organ transplant decisions, especially because the term “medically significant” remains undefined.³¹³ The fact that many decisions related to organ transplants are made during informal, unrecorded proceedings further heightens the potential for discrimination despite the existence of California’s law.

Where discrimination is suspected, the Uniform Anatomical Gift Act requires that courts

give priority review to any action brought under the statute in recognition of the risk of irreparable harm that a protracted battle to reverse a transplant denial entails.³¹⁴ But even on this front, the law simply states that courts are to provide priority review to “any action brought to seek any remedy authorized by law for purposes of enforcing compliance with this section.”³¹⁵ In other words, “[n]o specific penalties or remedies are set forth in the statute to encourage compliance,”³¹⁶ making the law less powerful in preventing discrimination.

Maryland’s Organ Transplant Nondiscrimination Law

Maryland’s 2015 legislation was based on model legislation written by ASAN,³¹⁷ and was unanimously passed by the Maryland legislature as the result of advocacy from The Arc of Maryland, the Maryland Disability Law Center, and ASAN.³¹⁸ Like its California and New Jersey predecessors, Maryland’s law fails to define what constitutes a “medically significant” reason to deny a person a transplant.³¹⁹ That said, the law does contain more specificity than prior legislation in other respects. For instance, the statute does not merely provide that a person with a disability cannot be denied a place on an organ transplant waiting list solely on the basis of that person’s disability.³²⁰ Instead, the statute goes further, specifically stating that a person with a disability cannot be placed “at a lower-

priority position on an organ transplant waiting list than the position at which the qualified individual would have been placed if not for the disability.”³²¹

The Maryland law imports ADA requirements by providing that “reasonable modifications in policies, practices, or procedures” should be made as necessary to provide access to transplant services.³²² It also requires transplant centers to “take such steps as may be necessary to ensure that an individual with a disability is not denied” transplant services “due to the absence of auxiliary aids and services.”³²³ Importantly, Maryland’s law specifies that supported decision making is among the types of auxiliary aids and services that must be provided to an individual with a disability when needed for a successful organ transplant, and makes clear that it need not be provided through a formal supported decision-making program.³²⁴

The statute also requires priority review for any actions brought under the law and explicitly states that courts should apply the ADA.³²⁵ In doing so, Maryland’s antidiscrimination statute does what California’s Uniform Anatomical Gift Act does not, and makes clear that actions may be brought seeking “injunctive or other equitable relief.”³²⁶ As a result, while Maryland does not impose the same deterrent fines for discrimination as Massachusetts does in its antidiscrimination statute, Maryland’s law nonetheless provides courts with guidance about available remedies.³²⁷

Chapter 5: Case Study: Lief and Paul

NCD's case study for this report focuses on Lief, a nonspeaking autistic child who struggled to obtain a heart transplant due to his disability. Lief types in order to communicate, and has several other characteristics of autistic people, including motor planning difficulties. When he was 9 years old, Lief developed a viral heart condition that threatened his life and he needed an immediate heart transplant. But two transplant hospitals rejected Lief as a patient solely because he was autistic. Lief's mother, Jessica Sunshine Bodey, publicized her son's case³²⁸ and strongly advocated for his transplant in an effort to save his life. Ultimately, Lucile Packard Children's Hospital at Stanford University gave Lief a heart transplant.

Lief was chosen for this case study both because his case was publicized in the media, and because it demonstrates how the assumptions of doctors and transplant center physicians about disability can lead to organ transplant discrimination.

This chapter also highlights the story of Paul Corby, an autistic adult with psychiatric disabilities who was denied access to a heart transplant on the basis of his disabilities. The societal prejudices that led to Mr. Corby being denied a transplant are similar to those faced by Lief.

Beginnings

Lief's struggle to survive began unexpectedly when he was 9 and developed a viral heart condition that, according to Ms. Bodey, caused his health to decline rapidly, leaving him near death within a couple of weeks. The virus flooded his heart with fluid, and the pressure from the fluid inside his heart tore Lief's heart muscle.³²⁹ Without a heart transplant, Lief had, at most, a few days or weeks to live. When Ms. Bodey arrived at a local children's hospital, the doctors told Ms. Bodey that "no facility would perform the transplant, and we should prepare for him to die."³³⁰

Ms. Bodey frantically called several organ transplant centers, desperately asking them if they would offer a heart transplant to her son. But the hospitals Ms. Bodey called rejected Lief as a candidate for a heart transplant, which Ms. Bodey believed was because Lief was autistic.³³¹

Mr. Corby, who is autistic and has psychiatric disabilities and also needed a heart transplant, was denied based on his perceived inability to comply with postoperative care and the organ transplant process due to his disabilities. The transplant center that evaluated him reportedly denied him because he was carrying a doll for comfort and could not name all 19 of the

medications he took—a feat which would be quite difficult for many people.

Disregard

During Lief's stay at the local children's hospital, the hospital appeared to Ms. Bodey to not even be attempting to save Lief's life; indeed, she was told as much by a nurse at the hospital.

Mr. Corby's mother, Karen Corby, reported that her son's primary care physicians behaved in a way that suggested that they dismissed the degree to which his life was at risk. Mr. Corby's physicians attributed many of his more striking symptoms, such as chest pains, vomiting, and high heart rate, to anxiety. The doctors eventually began to attribute his distress to stomach problems and never ordered any tests to check for heart problems.

Transplantation

According to Ms. Bodey, Lief only survived because a young doctor argued strenuously in their favor to Lucile Packard Children's Hospital at Stanford, which finally did accept Lief.

During the meeting with doctors at Stanford, Stanford saw Lief typing to communicate and, "at the 11th hour," accepted him.³³² Lief was quickly flown to Stanford where he received an LVAD.³³³

Ms. Bodey explained in her interview that upon her arrival at Stanford, she was told by the doctors that the transplant was unprecedented because they had never transplanted a heart into a child with autism as "severely affected" as Lief. Ms. Bodey noted that the very fact that Lief's transplant was seen as so revolutionary by Stanford meant that few children like Lief had ever been provided with a heart transplant before.

Lief's road to transplantation was still difficult even after he was accepted at Stanford. According to Ms. Bodey, his LVAD failed three times. In other words, Lief had to have five separate open-heart surgeries: four to insert LVADs, and one to transplant the heart.³³⁴ Nonetheless, Ms. Bodey reported Lief handled the surgeries extremely well, enduring a year in the hospital, when prior to his hospitalization, he had been unable sit in a restaurant for more than a few minutes. Lief himself attributed his endurance to the knowledge that his life was at stake.

Mr. Corby, as of yet, has not received a heart transplant. His mother reports that his condition is stable, but that because of previous rejections following evaluation, he does not wish to undergo any further evaluations unless he is guaranteed placement on the transplant recipient list. As a result, he and his family are not seeking further evaluations by transplant centers at this time.

Aftermath

According to Ms. Bodey, families of children with I/DD may, in fact, be better prepared to go through the rigorous transplant experience and to help their children handle postoperative care, due to their pre-existing support networks and familiarity with providing their children with similar care.

Lief continues to experience some physical disabilities as a result of the five separate open-heart surgeries he endured and the significant amount of time he spent in the hospital. Ms. Bodey said that while her son always had difficulties with motor skills, he used to be able to run and swim. He can no longer do either. Even so, Lief is enjoying his life and the pair

remain optimistic. Ms. Bodey said she has found it rewarding that she has been able to use their experience to connect with others and advocate for access to organ transplantation for people with disabilities. She and Lief testified at the Oregon House Committee on Health Care regarding the state's then-pending antidiscrimination legislation, where Lief thanked the committee for "doing the right thing."³³⁵

According to Karen Corby, the family spoke with DOJ concerning the discrimination, but the department did not take any action that

would rectify it. This disappointing result did not prevent the family from advocating for the development of state laws which would prevent individuals from experiencing discrimination in the future. Karen and Paul Corby were involved in state efforts to pass "Paul's Law," a Pennsylvania bill named after Mr. Corby that prohibits organ transplant discrimination when a denial is based solely on disability, including denials based on the need for a support system in order to comply with postoperative care.³³⁶

Chapter 6: Recommendations

Preface

Preventing discrimination on the basis of disability in the organ transplant process is challenging, particularly given that such discrimination is likely to involve pervasive biases and assumptions about people with disabilities, including that their quality of life may not justify the transplant, that disability is a contraindication for transplant due to non-compliance with post-operative treatment, and that organ transplants for people with disabilities will by definition have poorer medical outcomes than transplants for people without disabilities. Discrimination against people with disabilities may also be difficult to detect, occurring when a patient asks for a referral to an organ transplant center, or when that transplant center conducts (or refuses to conduct) what is often an informal evaluation process to determine whether the person with a disability is eligible for a transplant. But efforts can be taken at both the federal and state level to help prevent this oft hidden discrimination.

Action should also be taken to prevent discrimination in the organ procurement context, where people with disabilities may be especially vulnerable. Reforming the approach to organ

procurement to protect people with disabilities and ensuring that policies are in place to prevent people with disabilities from being targeted for organ procurement, will help protect people with disabilities from harm due to misplaced ideas about the value of the lives of people with disabilities.

Federal Guidance and Policy Reform

Federal guidance would assist physicians, organ transplant centers, and courts in avoiding discrimination against people with disabilities in the organ transplant process. In 2016, 30 members of Congress wrote a letter urging HHS's Office for Civil Rights (OCR) to issue guidance clarifying that: (1) organ transplant discrimination violates Title II of the Americans with Disabilities Act; (2) transplant entities must incorporate the patient's support network and services into eligibility policies and practices; and (3) people with disabilities should be provided with all necessary auxiliary aids and services they need for a successful organ transplant and postoperative regimen.³³⁷

No guidance was issued as a result of the 2016 letter to HHS, but guidance from DOJ and HHS should be issued now.

The Department of Justice (DOJ), in conjunction with the Department of Health and Human Services (HHS)

In addition to the items proposed in the 2016 letter, federal guidance should also:

- Emphasize that physicians must assess candidates for organ transplants individually, and without stereotypes about disability.
- Explicitly state that making assumptions regarding the post-transplant quality of life for people with disabilities violates federal law.
- Make clear that the ADA and Section 504 apply throughout the organ transplant process, including informal eligibility determinations, such that disability should only be taken into account to the extent that it can be clearly shown to be likely to impair successful transplantation.
- Encourage priority review of any cases brought challenging discrimination on the basis of disability in the organ transplant context in acknowledgment of the time-sensitive nature of a transplant denial.
- Delineate organ transplant center and physician responsibilities under Section 504 and the ADA to make reasonable modifications in their policies, practices, and procedures for individuals with disabilities seeking transplantation, and to ensure effective communication with those individuals including by providing, among other things, accessible digital and print materials for patients and families. Reasonable modifications should include ensuring that a patient has the necessary support services to comply with post-operative care.
- DOJ and HHS should also provide technical assistance to organ transplant centers and physicians in complying with the foregoing obligations. Issuing guidance and providing technical assistance would increase the likelihood that the application of the ADA, Section 504, and Section 1557 to the organ transplant process would be understood and that compliance with these laws would prevent disability discrimination in the organ transplant process. Organ transplant center policies that discriminate could more easily be challenged, and it may become easier to address the hidden discrimination inherent in the evaluation process.

(continued)

The Department of Justice (DOJ), in conjunction with the Department of Health and Human Services (HHS), *continued*

- HHS should fund a multi-year research and technical assistance project that investigates how transplant centers and organ procurement organizations respond to guidance about disability discrimination. To the extent appropriate, the results should be used to inform the provision of technical assistance, and perhaps further guidance, in this area.
- HHS should also award grants to fund a comprehensive study of patient selection criteria for people with disabilities in the organ transplant process. The results may be useful in informing the development of a uniform evaluation process for organ transplant centers to use when evaluating patients who may need organ transplants in order to help ensure that patients with disabilities receive a transparent evaluation that employs clear guidelines for transplant eligibility. This may alleviate some of the “hidden discrimination” otherwise inherent in the organ transplant process.
- Organ transplant centers should also be required to provide supported decision making when needed as a reasonable modification under the ADA, Section 504, and/or Section 1557 to assist people with disabilities in undergoing the organ transplantation process.
- Because “hidden discrimination” may still go undetected, even with a uniform evaluation process, and given the time-sensitive nature of organ transplants, DOJ and HHS should launch an online complaint system and hotline, coupled with a priority enforcement process, dedicated to those experiencing discrimination on the basis of disability in the organ transplant process.

UNOS/OPTN

Disability rights representatives should be included on the UNOS/OPTN Board and key committees in order to ensure that UNOS/OPTN continues to apply its waitlist criteria in a non-discriminatory manner, and to reform any UNOS/OPTN guidelines that could be interpreted by organ transplant centers as allowing people with disabilities to be kept off of the waitlist for a transplant.

State Legislation

With the exception of California’s Uniform Anatomical Gift Act, the state laws aiming to prevent discrimination on the basis of disability for organ transplants are relatively new. As a result, it is difficult at this stage to know whether they will be successful—or at least, more successful than federal law—in improving access to transplants for people with disabilities.³³⁸ Even so, enacting state laws preventing organ transplants from being denied on the basis of disability should promote awareness among physicians that this discrimination is illegal,

particularly given that doctors may otherwise be unaware that the ADA and Section 504 prohibit such actions.³³⁹

ASAN’s model legislation³⁴⁰ and Maryland’s subsequently enacted statute³⁴¹ that closely adheres to ASAN’s model are sources of guidance for states looking to implement their own legislation. But even this legislation can be improved on in order to meaningfully prevent discrimination, particularly during informal decision-making processes, and to ensure the effective adjudication of disputes.

States

At a minimum, state legislation seeking to prevent discrimination against people with disabilities in the organ transplantation process should:

- Prohibit the denial of necessary transplants on the basis of disability, including mental health disabilities, by doctors, hospitals, transplant centers, and other healthcare organizations.
- Require documentation of every stage of the organ transplant process to prevent hidden discrimination.
- Require the priority review of claims brought under the statute by courts in order to avoid the problems inherent in the slow-moving pace of litigation brought under the ADA and Section 504 and the fact that time can be a matter of life and death for someone in need of an organ transplant.³⁴²
- Require that eligibility determinations “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.”³⁴³ This helps prevent organ transplants from being denied to people with disabilities based on a physician’s concern that the patient will have difficulty complying with postoperative care.³⁴⁴

(continued)

States, *continued*

- Require that any auxiliary aids and services that people with disabilities need in order to access transplant services be provided.³⁴⁵
- Require “reasonable modifications in policies, practices, or procedures” for people with disabilities at each and every stage of the organ transplantation process. While such a provision is duplicative of an ADA requirement, including it in state legislation may help clarify the responsibilities and obligations healthcare providers must have to their patients.³⁴⁶
- Require covered entities, including organ transplant centers, to provide supported decision making as needed for people with disabilities, including making patient advocates available at organ transplant centers.
- Prohibit discrimination on the basis of disability in health plans that cover organ transplants.
- Specify the penalties for discriminating on the basis of disability, and make both injunctive relief and damages available.

The more states that adopt legislation preventing discrimination based on disability in the organ transplant process, the more likely it is that such discrimination will be prevented in reality. In fact, state legislation that includes provisions like those set forth above could also provide a basis for the creation of federal guidelines on this issue.

Organ Procurement Policy Reform

Discrimination on the basis of disability in the organ transplant process may be difficult to detect, let alone prevent. But given the clear indication that this discrimination exists, policy makers should take affirmative action to prevent it in the first place.

UNOS/OPTN

UNOS/OPTN should proactively work to prevent people with disabilities from being discriminated against in the organ procurement process while allowing them to make their own informed choices. To do so, UNOS/OPTN should:

- Ensure that individuals and families are able to make informed decisions about the withdrawal of life-sustaining treatment prior to and independent from any contacts from organ procurement organizations (OPOs). Those decisions should only be made once the family has received information in plain language regarding assessments that will be conducted, prognosis, and treatment options.
- Ensure that conscious potential donors are provided appropriate psychological counseling and support to live before OPOs are permitted to approach them.
- Prohibit any form of organ recruitment program that selectively targets people with disabilities, including newly injured individuals, people with amyotrophic lateral sclerosis (ALS), or other life-limiting conditions.
- Ensure that organ procurement requirements are clear and specific, comply with the nondiscrimination requirements of the ADA and Section 504, and include appropriate and proportional consequences for failure to comply.
- Incorporate disability information pertaining to the organ donor, including primary diagnosis and type of disability, in organ procurement data collection.
- Educate providers on best practices regarding determinations of brain death and current resources available to aid in making those determinations.

Appendix

(These tables were current as of March 2019.)

Table 1: Organ Transplant Centers by Region

Region Number	Total Number of Organ Transplant Centers
Region 1: Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Eastern Vermont	14
Region 2: Delaware, District of Columbia, Maryland, New Jersey, Pennsylvania, West Virginia, Northern Virginia	35
Region 3: Alabama, Arkansas, Florida, Georgia, Louisiana, Mississippi, Puerto Rico	30
Region 4: Oklahoma, Texas	29
Region 5: Arizona, California, Nevada, New Mexico, Utah	33
Region 6: Alaska, Hawaii, Idaho, Montana, Oregon, Washington	9
Region 7: Illinois, Minnesota, North Dakota, South Dakota, Wisconsin	23
Region 8: Colorado, Iowa, Kansas, Missouri, Nebraska, Wyoming	19
Region 9: New York, Western Vermont	16
Region 10: Indiana, Michigan, Ohio	20
Region 11: Kentucky, North Carolina, South Carolina, Tennessee, Virginia (aside from the Northern Virginia region)	25

Table 2: Organ Transplant Centers by State

State	Region/Regions	Number of Transplant Centers
Connecticut	1	2
Maine	1	1
Massachusetts	1	9
New Hampshire	1	1
Rhode Island	1	1
Vermont	1, 9	1
Delaware	2	2
District of Columbia	2	4
Maryland	2	3
New Jersey	2	6
Pennsylvania	2	18
West Virginia	2	1
Virginia	2, 11	7
Alabama	3	3
Arkansas	3	3
Florida	3	13
Georgia	3	4
Louisiana	3	4
Mississippi	3	1
Puerto Rico	3	2
Oklahoma	4	4
Texas	4	25
Arizona	5	5
California	5	22
Nevada	5	1
New Mexico	5	2
Utah	5	3
Alaska	6	No data
Hawaii	6	1
Idaho	6	No data
Montana	6	No data
Oregon	6	3

(continued)

Table 2: Organ Transplant Centers by State, *continued*

State	Region/Regions	Number of Transplant Centers
Washington	6	5
Illinois	7	9
Minnesota	7	6
North Dakota	7	2
South Dakota	7	2
Wisconsin	7	4
Colorado	8	4
Iowa	8	4
Kansas	8	1
Missouri	8	8
Nebraska	8	2
Wyoming	8	No data
New York	9	15
Indiana	10	3
Michigan	10	9
Ohio	10	8
Kentucky	11	3
North Carolina	11	5
South Carolina	11	2
Tennessee	11	9

Endnotes

- 1 “Transplant Trends,” United Network for Organ Sharing (UNOS), accessed March 25, 2019, <https://unos.org/data/transplant-trends>.
- 2 42 U.S.C. § 12102.
- 3 “Organ Procurement and Transplantation Network,” Organ Procurement and Transplantation Network, US Department of Health and Human Services, accessed March 25, 2019, <https://optn.transplant.hrsa.gov>.
- 4 “About UNOS,” United Network for Organ Sharing, accessed March 25, 2019, <https://unos.org/about>.
- 5 42 C.F.R. § 121.2.
- 6 “Members,” Organ Procurement and Transplantation Network, US Department of Health and Human Services, accessed March 25, 2019, <https://optn.transplant.hrsa.gov/members>.
- 7 “Frequently Asked Questions,” Transplant Living, United Network for Organ Sharing, 2019, <https://transplantliving.org/before-the-transplant/frequently-asked-questions>.
- 8 As disability discrimination in organ donation and organ procurement are different in both character and kind from disability discrimination during the organ transplantation process, they are not discussed in this subsection. A brief subsection on disability discrimination in organ procurement can be found in Chapter 1 of this report.
- 9 “What Every Patient Needs to Know,” United Network for Organ Sharing, 2016, accessed July 30, 2019, <https://unos.org/wp-content/uploads/unos/WEPNTK.pdf>; “Referrals,” Comprehensive Treatment Center, Johns Hopkins Medicine, accessed March 12, 2019, https://www.hopkinsmedicine.org/transplant/patient_information/experience/before_transplant/referral_faqs/index.html.
- 10 “What Every Patient Needs to Know,” United Network for Organ Sharing.
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- 12 42 C.F.R. § 121.6(c).
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- 201 "Some transplant centers have been able to overcome compliance problems by having frequent contact with their patients." Orentlicher, "Deconstructing Disability," 66.
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- 203 Guidance states that a medical provider could not use surcharges to cover the cost of providing a patient with a disability or that patient's companion with an interpreter because "the 1991 [ADA] title III regulation prohibits the imposition of surcharges to cover the costs of necessary auxiliary aids and services." 28 C.F.R. Appendix A to Part 36. "[P]eople with disabilities, like any patients in a program or service covered by the ADA or Rehabilitation Act, should be provided with all necessary auxiliary aids and services they need for a successful organ transplant and postoperative regimen. Specifically, Title II of the ADA and the Rehabilitation Act requires that a person with a disability be provided with any auxiliary aids they need in order to access any public or federally funded services." Representative Honda to Director Samuels, October 12, 2016.
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National Council on Disability
1331 F Street, NW, Suite 850
Washington, DC 20004