
**THE DEFIBRILLATION OF NOTA: HOW
ESTABLISHING FEDERAL
REGULATION OF WAITLIST
ELIGIBILITY MAY SAVE ORGAN
TRANSPLANT PATIENTS WITH
DISABILITIES FROM FLAT-LINING**

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I. INTRODUCTION

Imagine this: thirty-five-year-old identical twin males are admitted into a hospital for congestive heart failure. Neither twin smokes nor drinks. Neither has other underlying medical conditions. There is, however, one distinct difference between them: at birth, twin “A,” Alex, was delivered normally, but twin “B,” Brian, had his umbilical cord wrapped around his neck, causing oxygen deprivation and resulting in moderate mental disability.¹ As adults, Alex is completely independent, but Brian is not, as he lives with his elderly parents. Both twins are stubborn, but a few times, Brian has reacted especially negatively when placed in new and stressful situations.

The twins have the same doctor who determines that both are equally sick, concluding that each will survive only with a heart transplant. Although it seems Alex can comply with postoperative treatment—first, with help from family and later, alone—Brian may not be able to comply by himself. His parents and his sister, however, are willing to provide Brian with the additional support he needs to comply, such as ensuring he takes his medication, follows other medical restrictions, and attends regular follow-up appointments. If Brian can comply with the postoperative treatment with or without help from his family, the doctor predicts Brian’s long-term prospects for life-prolongation will be the same as Alex’s prospects.

After evaluating the twins, the doctor has to decide independently whether to place each on the national heart transplant waitlist. Knowing the above, what should the doctor decide? Should Alex be placed on the heart transplant waitlist? Should Brian? Should the doctor consider Brian’s mental disability when making his decision? Should it matter that Brian’s parents and sisters have agreed to provide him with additional support?

Although the particulars of this scenario are unlikely, they juxtapose the tensions associated with allocating scarce resources, such as organs for transplantation, to individuals with disabilities. In reality, many severely ill persons with disabilities compete for lifesaving medical care with others

1. See *infra* note 154 and accompanying text (considering the application of psychosocial criteria for patients with severe or even extreme intellectual disabilities, such as anencephaly).

equally ill, but not disabled. Recently, there have been numerous allegations that individuals with mental disabilities have been denied access to the national transplant waitlists because of their disabilities. These are individuals such as Paul Corby, an adult with autism in need of a heart transplant, and Amelia Rivera, a child with Wolf-Hirschhorn Syndrome in need of a kidney.²

The question of whether each twin should be placed on the waitlist necessarily requires an individual determination of the person's medical need and likelihood of postoperative success, with or without assistance over time, but it cannot be made in a vacuum. Personal and societal values may creep in, consciously or not, affecting the likelihood of an individual being placed on the transplant waitlist. This is especially true because, as the U.S. transplant system currently stands, federal laws and regulations govern the organ allocation process after a patient is placed on the waitlist, but not before. There are no federal laws or regulations specifying who should be placed on an organ transplant waitlist or what specific criteria hospitals and doctors should use to determine waitlist eligibility. Transplant centers and their physicians, thus, are left to determine their own standards and criteria for determining a patient's eligibility for placement on an organ transplantation waitlist. The lack of uniformity in the eligibility process causes concerning results: a patient deemed ineligible at a hospital in Texas may be eligible at a hospital in California, or for that matter, ineligible at a hospital in Dallas, but eligible at one in Austin. With scarce, lifesaving resources like organs, however, the lack of uniformity in eligibility criteria between centers opens the door to allegations of unfair treatment, bias, and discrimination. Hence, it is imperative that patients receive uniform, objective, and measurable evaluations of their eligibility for waitlist placement to ensure fairness in the federally-regulated-allocation process.

In this Note, I will discuss how the current lack of federal legislative and regulatory oversight during the initial transplantation evaluation stage increases the likelihood of eligibility decisions based on improper evaluations of social worth and psychosocial³ compliance ability, in violation of the Americans with Disabilities Act ("ADA"). Part II will provide an overview of the current U.S. transplantation system and discuss how considerations of avoiding organ wastage determine transplantation policies in relation to mental disabilities and psychosocial evaluation

2. See *infra* Part IV.A–B (discussing these cases in greater detail).

3. See *Psychosocial Definition*, MERRIAM-WEBSTER, <http://www.merriam-webster.com/dictionary/psychosocial> (last visited Nov. 5, 2013) (defining psychosocial criteria used to analyze both psychological and social behavioral aspects of an individual).

criteria. Part III will discuss current transplantation and disability laws and how these laws may interact to protect individuals with mental disabilities in need of transplantation. Part IV will discuss recent and historical allegations of unfair treatment of patients with mental disabilities in the waitlist eligibility process. Part V will outline the state legislative and federal regulatory backlash to these allegations of unfair treatment. Part VI will suggest possible policy changes to current federal laws and regulations to regulate uniformly transplant center and physician use of eligibility evaluation criteria to avoid ADA violations. Finally, Part VII concludes.

II. THE DEVELOPMENT OF THE CURRENT U.S. ORGAN TRANSPLANTATION SYSTEM

Since the first successful organ transplant in 1954, society has struggled to reconcile considerations of scarcity, need, utility, and fairness in the transplantation process. With the enactment of the National Organ Transplant Act (“NOTA”) in 1984⁴ and Health and Human Services’ (“HHS”) Final Rule in 1998,⁵ the federal government has attempted to create a fair, transparent, and accountable transplantation process for its citizens that is both morally and medically superior to the 1960s “god squad”—community members deciding who would receive limited kidney dialysis treatments.⁶ Regulatory schemes such as the transplantation process created by NOTA, however, are inherently imperfect, and are fraught with value conflicts and indeterminacies found whenever ethics intersects with the law. Organ scarcity will always result in some form of inequity because it requires society to choose to offer an organ to one person or another. How should we decide? Who should we consider eligible in the first place? These decisions will necessarily favor one group or person over another. In the context of transplantation, how we structure our system is a decision of life or death for many of our citizens. The legislature tries to create policies that maximize benefits to society as a whole, but maximization is necessarily a moral determination, and the

4. Pub. L. No. 98-507, 98 Stat. 2339 (1984).

5. 41 C.F.R. § 121 (1998).

6. Albert R. Jonsen, *The God Squad and the Origins of Transplantation Ethics and Policy*, 35 J.L. MED. & ETHICS 238, 238 (2007). See also David Sanders & Jesse Dukeminier, Jr., *Medical Advance and Legal Lag: Hemodialysis and Kidney Transplantation*, 15 UCLA L. REV. 357, 377–79 (1968) (describing the Seattle Artificial Kidney Center’s process for kidney dialysis treatment and raising ethical considerations related to the process); Shana Alexander, *They Decide Who Lives, Who Dies*, LIFE, Nov. 9, 1962, at 102, 125, available at http://books.google.com/books?id=qUoEAAAAMBAJ&printsec=frontcover&source=gbs_ge_summary_r&cad=0#v=onepage&q&f=false (first reporting on the Seattle Artificial Kidney Center’s decisionmaking process).

criteria chosen to implement it are uncertain and possibly even arbitrary to some degree. In light of recent allegations that individuals with mental disabilities have been unfairly treated while seeking transplantation, the legal community must again review our system's shortcomings, reflect on how this comports with our ethical ideals, and decide if society will condemn or condone the issue through the judicial, legislative, or regulatory process.

Mental disability presents a unique challenge for transplantation policy because it may be used either as a legitimate consideration for candidacy, or unfairly to deny individuals treatment.⁷ As David Orentlicher has argued, “[A] rationing system that allocates care on the basis of degree of benefit will often result in unfair discrimination against sicker patients or patients with more disabling conditions.”⁸ When an individual's mental disability would inhibit him from complying with postoperative medical treatment, it may be a legitimate reason for denial if the individual does not have a sufficient support system to ensure compliance.⁹ Clearly, much depends on the interplay between the nature and degree of disability, on the one hand, and the effectiveness of the support system, on the other. However, when an individual's mental disability would not, at the bottom line, affect his postoperative success, such as when he can comply with treatment with or without assistance, using mental disability as an absolute or relative contraindication¹⁰ to eligibility before individual evaluation of the patient would unfairly deny the patient lifesaving treatment.¹¹ In the transplantation context, mental disability is often set out as a relative contraindication even before the patient is evaluated, requiring the patient with mental disabilities to establish sufficient compliance ability in order for the physician to consider placing the patient on a waitlist. It can also be set out as an absolute contraindication, which would deny a patient with a

7. Although extraneous physical disability can result in similar and equally concerning problems, this Note focuses on the impact of mental disability to more clearly analyze the use of mental competence and compliance as psychosocial criteria during the eligibility stage. However, many considerations discussed herein apply with equal force to individuals with physical disabilities (beyond their organ failure).

8. David Orentlicher, *Destructuring Disability: Rationing of Health Care and Unfair Discrimination Against the Sick*, 31 HARV. C.R.-C.L. L. REV. 49, 53 (1996).

9. For the purposes of this Note, mental disability means any learning, comprehension, or psychological disability, including what might loosely be referred to as “volitional” or impulse control disorders.

10. See *Contraindication Definition*, MEDLINEPLUS, www.nlm.nih.gov/medlineplus/ency/article/002314.htm (last updated Jan. 21, 2013) (defining contraindication as “a specific situation in which a . . . procedure . . . should not be used because it may be harmful to the patient”).

11. This is assuming that the individual meets all other medical requirements necessary to receive a transplant.

mental disability access to transplantation automatically without individual review.¹² These standards create a higher standard for transplant eligibility for individuals with mental disabilities than for the general population, in which there is no presumption of contraindications before evaluation. Ultimately, although mental disability may affect the postoperative course of action, it does not necessarily affect the immediate lifesaving result.

A. RATIONING: SCARCITY AND WASTE IN THE TRANSPLANTATION PROCESS

Until the 1990s, many hospitals and physicians considered any salient disability as an absolute or strong contraindication to transplantation due to concern that individuals with mental disabilities would be less compliant with postoperative medical treatment than the general population, putting them at greater risk for complications and, ultimately, organ rejection. Such concern for individuals with mental disabilities as a class may be misguided by assumptions about the abilities of such individuals because it does not allow for individual evaluation of the patient. To be sure, concern regarding a specific patient's ability to comply with postoperative treatment after thorough evaluation may be justified. Since organs are a scarce, lifesaving resource, it is imperative that they are not wasted on individuals who cannot or will not comply with medical treatment. Giving a scarce resource to a noncompliant patient maximizes neither the individual's life nor societal utility for the organ. Furthermore, it goes against HHS's regulation that transplant centers use organs for their best uses and avoid waste.¹³

The practical application of scarcity and waste considerations for transplantation is complex. What is waste? Who is likely to cause it? What factors should be used in determining the likelihood that an organ will be wasted? These questions do not only involve medical determinations about a patient's viability; they also involve social value determinations.

1. What Is Waste and Who Gets to Decide?

What constitutes waste is based, in significant part, on society's values and preferences; hence, the determination that allocating a specific organ to a specific individual is wasteful—even if the criteria used to evaluate waste

12. See *infra* text accompanying notes 31–37.

13. Organ Procurement and Transplantation Network (“OPTN”), 42 C.F.R. § 121.8(a)(2), (5) (2013). Having an allocation system based primarily on need and utilitarian best use can create problems, however, because these goals sometimes work against each other. For example, saving the neediest patient will not necessarily maximize overall utility.

are based on objective medical standards¹⁴—can never be truly value free. Under the current regulatory scheme for organ transplantation, value judgments abound, whether made by hospitals and physicians in the initial evaluation stage, or by the United Network of Organ Sharing (“UNOS”), the government contractor for the Organ Procurement and Transplantation Network (“OPTN”),¹⁵ during the ranking of waitlist patients and distribution of available organs.¹⁶

The initial stage in the transplantation process involves physician referral and evaluation of the patient’s candidacy for transplantation.¹⁷ This stage has no regulation except for generalized professional standards, leaving physicians wide discretion to determine what constitutes waste and how to evaluate risks of waste based on their medical judgment.¹⁸ The result is that there are no uniform guidelines or criteria for hospitals and physicians to determine what is waste or the likelihood that someone will create it.¹⁹ Many times, these determinations center on compliance issues, requiring transplantation centers to employ their own list of psychosocial criteria, which they deem medically relevant, and to specify thresholds to determine a patient’s risk of noncompliance. Such factors may include evidence of (1) past compliance issues, (2) learning, comprehension, or

14. The choice of what medical criteria will determine waste also involves a moral evaluation of efficacy. The choice of which criteria to include can unintentionally hurt individuals with disabilities if they are disparately disadvantaged by the criteria; however, such criteria would only be discriminatory if chosen because of and not in spite of their disparate impact. To illustrate the idea of objective-appearing “factual” criteria requiring moral evaluation, consider the following: a woman generally can have an abortion up until viability of her fetus, but the threshold for what constitutes viability is an imprecise determination. Until a fetus is carried to term, viability is always less than 100 percent. At what point in this spectrum, then, is a fetus viable enough to prohibit abortion? Is a 10 percent chance of survival enough? 30 percent? 50 percent? In this light, the current trimester system is, to some extent, an arbitrary but necessary threshold that society has made based on its values and conceptions of life. This same process is also present in the transplantation process.

15. See *infra* Part III.B (discussing the provisions of NOTA).

16. See Neal R. Barshes et al., *Justice, Administrative Law, and the Transplant Clinician: The Ethical and Legislative Basis of a National Policy on Donor Liver Allocation*, 23 J. CONTEMP. HEALTH L. & POL’Y 200, 211–12 (2007) (discussing that although the federal government may have authority over transplantation, it has very minimal involvement in it because it contracts out for creation and oversight of the allocation process and leaves the evaluation process entirely in the hands of individual physicians and transplant centers).

17. TALKING ABOUT TRANSPLANTATION: WHAT EVERY PATIENT NEEDS TO KNOW, UNITED NETWORK ORGAN SHARING 7 (2013), available at <http://www.unos.org/docs/WEPNTK.pdf>.

18. Eric F. Galen, Note, *Organ Transplantation at the Millennium: Regulatory Framework, Allocation Prerogatives, and Political Interests*, 9 S. CAL. INTERDISC. L.J. 335, 375–77 (1999).

19. Such decentralized delegation during the evaluation stage is the result of (1) medical lobbies resisting regulation of medical judgment and (2) the inherent difficulty in creating a coherent and fair process. *Cf. id.* at 341 (describing the lobbying action surrounding HHS’s Final Rule).

psychological issues, (3) drug or alcohol abuse, and (4) familial support.²⁰ The selection and application of these psychosocial factors intermingles societal and personal value judgments with medical criteria.

If a patient is considered eligible for transplantation during the evaluation stage, he is placed on the national organ waitlist, regulated by UNOS. Through NOTA, the federal government has tasked UNOS with creating the national allocation policies for each type of organ and overseeing the distribution of these organs based on the allocation criteria set forth in its policies. Societal value judgments affect the allocation policies in that, although the criteria selected are primarily based on sound and objective medical standards, the decision to use one standard or factor over another and the subsequent weight of each factor in determining allocation priority is a value choice by UNOS. Additionally, the liver and kidney allocation policies created by UNOS specify that “the final decision to accept a particular organ will remain the prerogative of the transplant surgeon and/or physician responsible for the care of the candidate,” which necessarily delegate some normative responsibilities to the physician in determining the best-suited transplantation candidate.²¹ As formulated, however, this policy may overdelegate such authority. This authorization leaves open the possibility that a physician could reject an organ for an individual with a disability in favor of allocating it to another individual further down the list, essentially jumping over one individual to give to another individual with lower priority.²² The likelihood of this, however, may be mitigated by the fact that physicians must submit explanations to UNOS explaining why they rejected the organ for the specific individual.²³

Since neither the initial evaluation nor allocation (final selection) stages of the transplantation process are entirely objective, how then do we ensure that the process for determining waste is fair? Generally, an approach to ensuring fairness is to create a system with transparency, accountability, and uniformity. The current transplantation system generally creates this for the allocation stage; it has a formal public

20. The application of these factors, however, is not regulated or required.

21. ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK, ORGAN DISTRIBUTION: ALLOCATION OF DECEASED KIDNEYS § 3.5 (2012) [hereinafter OPTN KIDNEY POLICY], available at http://optn.transplant.hrsa.gov/PoliciesandBylaws2/policies/pdfs/policy_7.pdf. OPTN uses similar language in its liver transplant policy. ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK, ORGAN DISTRIBUTION: ALLOCATION OF LIVERS § 3.6 (2012) [hereinafter OPTN LIVER POLICY], available at http://optn.transplant.hrsa.gov/PoliciesandBylaws2/policies/pdfs/policy_8.pdf.

22. This is possible if a physician has two patients on the waitlist with similar rankings.

23. OPTN KIDNEY POLICY, *supra* note 21, § 3.5; OPTN LIVER POLICY, *supra* note 21, § 3.6.

comment period required for all allocation policy changes,²⁴ a complaint process,²⁵ and Medicaid and Medicare penalties for transplant centers that violate rules and regulations.²⁶ Although current allocation policies may not be ideal, their uniformity and regulation provides stability and fairness because once on the waitlist, an individual can objectively calculate his rank based on the scoring formula.²⁷ This may not solve every instance of discrimination or unfair disadvantage, but it gives individuals a tool to evaluate their treatment in comparison with others and disincentivizes unfair treatment through HHS's ability to review individual cases.²⁸

At the initial evaluation stage, there are no formal criteria guidelines or requirements for evaluating a patient's candidacy for waitlist placement required by federal law. This makes transparency virtually nonexistent and accountability all but impossible because it is difficult to prove improper treatment if the patient has no objective standard to compare it to. Thus, the evaluation stage poses a greater threat not only of unfair treatment generally, but also of discrimination against individuals with mental disabilities.

2. Who Is Likely to Cause Waste?

Assuming that candidates considered for transplantation would medically benefit from the procedure, three groups of individuals would cause organ waste:

- (1) Individuals who likely are too ill to survive surgery or will not survive long postoperatively;
- (2) Individuals who are too stable to necessitate immediate action; and
- (3) Individuals who are ill enough to immediately require transplantation and have a good prognosis, but have a high risk of noncompliance.²⁹

24. 42 C.F.R. § 121.4(b)(1) (2013).

25. *Id.* § 121.4(d).

26. *Id.* § 121.10(c).

27. *E.g.*, OPTN KIDNEY POLICY, *supra* note 21, § 3.5.3.

28. This is assuming that the physicians list individuals based on their correct medical evaluation scores. *See* 42 C.F.R. § 121.4(d) (2013) (allowing "[a]ny interested individual or entity [to] . . . submit to the [HHS] Secretary in writing critical comments related to the manner in which the OPTN is carrying out its duties"); *id.* § 121.10(b)(3) (requiring the OPTN to review OPOs and transplant programs that are suspected of noncompliance with federal regulations or OPTN policies at the request of the HHS Secretary); ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK, ORGAN DISTRIBUTION: UNOS PATIENT WAITING LIST § 3.2.7 (2013), *available at* http://optn.transplant.hrsa.gov/PoliciesandBylaws2/policies/pdfs/policy_4.pdf (mandating that transplant hospitals provide patients with information on how to report grievances or concerns to the OPTN).

29. For the purposes of this Note, I will only evaluate the third category of individuals.

Individuals with mental disabilities are often included as patients in the third noncompliance group above. Until the early 1990s, mental disabilities were commonly considered absolute contraindications to transplantation; however, perceptions are slowly changing to allow greater access to transplantation for individuals with mental disabilities.³⁰

A 2012 study by Emma Samelson-Jones, Donna M. Mancini, and Peter A. Shapiro analyzed transplant centers' use of mental disability as a contraindication to transplantation success and the postoperation results of five transplant recipients with mental disabilities, concluding that the more severe the mental disability, the more likely it is that the center will view it as an absolute or relative contraindication to transplantation for noncompliance reasons. This is especially true for hearts and livers, as opposed to kidneys, because of the greater prevalence of live donation for kidneys, and because of the widespread availability of kidney dialysis treatment to support individuals until a close match can be found. A survey by Marilee A. Martens, Linda Jones, and Steven Reiss corroborates Samelson-Jones's findings.³¹ In the Martens survey, heart patients with mental disabilities fared the worst. 25.6 percent of transplant centers viewed an IQ of 50 to 70 as an absolute contraindication to transplantation, 59.0 percent viewed it as a relative contraindication, and 15.4 percent found no contraindication.³² If the heart patient's IQ was under 50, 74.4 percent of centers viewed it as an absolute contraindication, 19.2 percent viewed it as a relative contraindication, and 6.4 percent found no contraindication.³³ After hearts, 10.9 percent of transplant centers viewed an IQ of 50 to 70 as an absolute contraindication to liver transplantation, 69.6 percent viewed it as a relative contraindication, and 19.6 percent found no contraindication.³⁴ If the liver patient's IQ was under 50, 45.7 percent of centers viewed it as an absolute contraindication, 41.3 percent viewed it as a relative contraindication, and 13.0 percent found no

30. Emma Samelson-Jones, Donna M. Mancini & Peter A. Shapiro, *Cardiac Transplantation in Adult Patients with Mental Retardation: Do Outcomes Support Consensus Guidelines?*, 53 PSYCHOSOMATICS 133, 135 (2012).

31. See generally Marilee Martens, Linda Jones & Steven Reiss, *Organ Transplantation, Organ Donations and Mental Retardation*, 10 PEDIATRIC TRANSPLANTATION 658 (2006) (surveying transplant centers' use of mental disability as an established relative or absolute contraindications to transplantation).

32. *Id.* at 659 (attributing the chart from James L. Levenson & Mary Ellen Olbrisch, *Psychosocial Evaluation of Organ Transplant Candidates: A Comparative Survey of Process, Criteria, and Outcomes in Heart, Liver, and Kidney Transplantation*, 34 PSYCHOSOMATICS 314 (1993)).

33. *Id.*

34. *Id.*

contraindication.³⁵ Most favorably, 2.6 percent of transplant centers viewed an IQ of 50 to 70 as an absolute contraindication to kidney transplantation, 51.3 percent viewed it as a relative contraindication, and 46.1 percent found no contraindication.³⁶ If the kidney patient's IQ was under 50, 24.0 percent of centers viewed it as an absolute contraindication, 51.9 percent viewed it as a relative contraindication, and 24.0 percent found no contraindication.³⁷ Table 1 below summarizes the above statistics.

TABLE 1. Percentage of Transplant Centers Using IQ as a Contraindication to Transplantation

	<i>Cardiac</i>	<i>Liver</i>	<i>Renal</i>
IQ 50–70			
Absolute Contraindication	25.6%	10.9%	2.6%
Relative Contraindication	59.0%	69.6%	51.3%
No Contraindication	15.4%	19.6%	46.1%
IQ < 50			
Absolute Contraindication	74.4%	45.7%	24.0%
Relative Contraindication	19.2%	41.3%	51.9%
No Contraindication	6.4%	13.0%	24.0%

Source: This table is adapted from Martens, Jones & Reiss, *supra* note 31, at 659.

Notwithstanding the prevalent practice of using mental disability as a contraindication to a transplantation's medical long-term success, recent medical studies that review compliance and longevity results of individuals with mental disabilities provide evidence that their average compliance rates are similar to—and sometimes better than—the average compliance rates for the general population.³⁸ This suggests that predetermining mental disability to be an absolute or relative contraindication to transplantation eligibility may be inappropriate. Thus, using psychosocial criteria such as compliance to help determine waitlist eligibility must be carefully applied on an individual basis—without presupposing a patient's ability or lack

35. *Id.*

36. *Id.*

37. *Id.*

38. *Id.* at 661 (“[R]ates of success of renal transplantations in people with [mental disabilities] may be comparable to nationally reported rates for the general population as a whole.”).

thereof—to ensure that physicians are not making social worth determinations and do not violate the ADA or other state laws protecting individuals with mental disabilities during the transplantation process.³⁹

Moreover, the Samelson-Jones review of five cardiac transplantation recipients with mental disabilities at New York-Presbyterian Hospital Columbia University Medical Center between 1978 and 2010 found that

[p]eople with mental retardation can receive long-term benefit from heart transplantation when they have the cognitive and social support necessary to ensure adherence to post-transplant regimens . . . [and that t]here is no ethical or medical reason for guidelines to consider mental retardation, in and of itself, a contraindication to heart transplantation.⁴⁰

Unfortunately, the available sample size of individuals with mental disabilities was sparse: there were only five heart transplant recipients with mental disabilities who received heart transplants out of 2194 performed at the center during this period.⁴¹ Nevertheless, those five individuals had “[s]urvival times to date rang[ing] from 4 to over 16 years, with four of five patients still alive, yielding a median survival to date of 12 years after transplantation”;⁴² the average cardiac patient survival rate for the general population is approximately nine years.⁴³ Additionally, noncompliance was “a clinically significant factor in only one [of the] case[s], in which medical non-adherence was linked to a functional decline in the primary caretaker, and probably contributed to the patient’s death.”⁴⁴ Overall, the recipients’ average postoperative noncompliance rate for immunosuppressant treatment was 20 percent; this is lower than the noncompliance rate among the general population, which is approximately 23 percent.⁴⁵ This suggests

39. See *infra* Part III.E (discussing who is likely to cause waste and how the ADA applies to the transplantation process).

40. Samelson-Jones, Mancini & Shapiro, *supra* note 30, at 133. See also Orentlicher, *supra* note 8, at 66 (arguing that transplant centers also may have an affirmative duty to provide individuals with mental disabilities who also have a high likelihood of noncompliance with a support system to ensure compliance); *infra* Part III.E (discussing ADA reasonable accommodations in the transplantation process).

41. Samelson-Jones, Mancini & Shapiro, *supra* note 30, at 134.

42. *Id.* at 137.

43. M.J. Everly, Abstract, *Cardiac Transplantation in the United States: An Analysis of the UNOS Registry*, 2008 CLINICAL TRANSPLANTS 35, available at <http://www.ncbi.nlm.nih.gov/pubmed/19708444>.

44. Samelson-Jones, Mancini & Shapiro, *supra* note 30, at 137.

45. *Id.* Since physicians may be less inclined to place individuals with mental disabilities on the transplant waitlists, these cases may be representative of ones that have already undergone intensive compliance screening and may not be accurate in determining compliance in the population of individuals with disabilities as a whole. Nevertheless, these cases show that compliance is not always an issue for individuals with mental disabilities.

that using mental disability as a contraindication to transplantation compliance or success generally may create a “higher standard” for individuals with mental disabilities to overcome to receive a transplant than required of the general population.⁴⁶ To prevent the application of a higher standard for individuals with mental disabilities, the researchers in the Samelson-Jones study support evaluating the compliance abilities of individuals with mental disabilities in the same way as children and the general population are evaluated.⁴⁷ Table 2 below summarizes the compliance data for the five individuals with mental disabilities in the Samelson-Jones study.

46. *Id.* Essentially, using mental disability as a contraindication to transplantation creates a rebuttable presumption that the individual is likely to be noncompliant. The burden is then on the family or the individual to show that compliance will not be an issue. On the other hand, the general population is presumed compliant unless evidence supports otherwise. This makes the process easier for the general population to prove their candidacy than those with mental disabilities. If, as the studies suggest, mental disability does not indicate noncompliance and, therefore, waste, then it should not be considered an automatic contraindication to transplantation.

47. *Id.*

TABLE 2. Columbia University Medical Center Compliance with Mental Disabilities

	<i>Mr. A</i>	<i>Mr. B</i>	<i>Mr. C</i>	<i>Mr. D</i>	<i>Mr. E</i>
IQ	68	76	“preschool-aged child”	70-79	Below 20
Age	36	21	30	37	50
Postsurgery Living	With parents	With mother	24/7 health attendant	Divorced, living alone	With mother
Compliance	Takes medication with minimal supervision	Sometimes “lax” about blood work, but good health	No independent compliance	Attending psychiatric drop in program and has nurse home visits twice a day	Mother supported—compliance declined as her health declined
Survival Length and Health	16 years / Alive and in good health	13 years / Alive and in good health	12 years / Alive and in good health	8 years / Alive and in good health	4 years / Deceased (transplant related)

Source: Samelson-Jones, Mancini & Shapiro, *supra* note 30, at 134–35.

In a similar vein, the Martens study of survival rates for individuals with mental disabilities post-transplantation also shows that

patient survival rates . . . were . . . 100 [percent] at one-y[ear] follow up and . . . 90 [percent] at three-y[ear] follow up. [Comparatively, the] OPTN has reported national patient survival rates for renal transplantation of 95 [percent] at one-y[ear] follow up and 90 [percent] at three-y[ear] follow up (based on OPTN data as of Jan[uary] 27, 2006).⁴⁸

Some transplantation centers studied by Martens “reported good post-transplant medication compliance when patients had support from family members or concerned caregivers.”⁴⁹ This indicates that the presence of an underlying disability may trigger extra care on behalf of either the patient or his caregivers, yielding greater postoperative success than the general population. Table 3 below summarizes the survival data from the Martens

48. Martens, Jones & Reiss, *supra* note 31, at 661.

49. *Id.*

study of one- and three-year survival rates.

TABLE 3. One- and Three-Year Survival Rates for Renal Transplant Recipients with Mental Disabilities

<i>Transplant Center</i>	<i>Age at Transplant</i>	<i>1-Year</i>	<i>3-Year</i>
University of Illinois, Chicago, IL	16, 17, 17, 22, 23, 26, 31, 45	8 / 8	8 / 8
Children's Hospital, Stockholm, Sweden	1, 1, 5, 5, 7, 7, 9, 11, 12, 15 (three cases unknown)	13 / 13	12 / 12
North American Pediatric Renal Transplant Cooperative Study	6–12 (8 cases), 13–17 (5 cases), > 17 (1 case)	Not available	11 / 14
The Hospital for Sick Children, Toronto, Canada	7, 10	2 / 2	1 / 1
Massachusetts General Hospital, Boston, MA	36, adult (age not specified)	2 / 2	2 / 2
St Christopher's Hospital for Children, Philadelphia, PA	14, 20	2 / 2	0 / 1
Children's Hospital of Philadelphia, Philadelphia, PA	10, 11, 13, 17, 19, 34	6 / 6	4 / 4
Total across all studies		33 / 33	38 / 42

Source: This table is adapted from Martens, Jones & Reiss, *supra* note 31, at 661 (citing statistics from 2005–2006 and cautioning that, similar to the Samelson-Jones study, the sample size was small and “there may [have] be[en] some bias in favor of positive outcomes . . . if surgeons were more likely to report successful cases than unsuccessful cases . . . [or if] only those patients who were healthy except for their failing organ [were included in the study]?”).

3. What Factors Determine the Likelihood an Organ Will Be Wasted?

During the evaluation process, the use of psychosocial criteria, such as mental competence and the likelihood of compliance, to establish an individual's eligibility for transplantation seeks to evaluate the risk that a transplant will be unsuccessful for reasons other than medical suitability. The inquiry essentially asks if the patient is competent enough to understand the transplantation process, medical procedure, and subsequent medical responsibilities and, if so, whether the patient can comply with the necessary postoperative medical regimen to make the surgery a success in the long term. Although, as observed, psychosocial criteria can be helpful in determining the likelihood of long-term transplantation success, they also can be dangerous evaluative tools because their subjectivity and

inherent moral content make it difficult to establish whether they legitimately correlate to long-term survivability or are instead a placeholder for social worth.⁵⁰ Thus, some physicians in the medical community advocate that there should be regulation or guidance on the use of psychosocial criteria akin to those created by UNOS in the allocation stage.⁵¹

In the post-god squad era, the transplantation community has categorically rejected using social worth as a factor for determining an individual's eligibility for transplantation; however, it is questionable whether all physicians use the concept of social worth in an analytically acceptable manner.⁵² For example, the psychosocial criterion of

50. Social worth has components of judgments about intrinsic moral worth (for example, smart people are morally more valuable than nonsmart people) and instrumental moral worth (individuals with disabilities draw resources from the "more deserving," thus lowering overall utility). See U.S. NAT'L LIBRARY OF MED., SOCIAL DESIRABILITY: SUBJECT HEADING, MEDICAL SUBJECT HEADING, http://www.nlm.nih.gov/cgi/mesh/2013/MB_cgi?mode=&term=Social+Desirability (last visited Nov. 9, 2013) (defining social worth as "[a] personality trait rendering [an] individual acceptable in social or interpersonal relations[, which] is related to social acceptance, social approval, popularity, social status, leadership qualities, or any quality making him a socially desirable companion"). Cf. Mandeep R. Mehra, *Listing Criteria for Heart Transplantation: International Society for Heart and Lung Transplantation Guidelines for the Care of Cardiac Transplant Candidates—2006*, 25 J. HEART & LUNG TRANSPLANTATION 1024, 1034 (2006) (noting the danger in using psychosocial criteria to improperly make social worth determinations).

51. Samelson-Jones, Mancini & Shapiro, *supra* note 30, at 135. See also *infra* Part VI (suggesting possible legislative, regulatory, and policy changes to better protect individuals with mental disabilities).

52. For example, I recently spoke with a heart transplant surgeon who is actively practicing and is involved with creating internal hospital and professional society policies regarding the use of psychosocial criteria for transplantation eligibility. The surgeon stated that the primary reason that the surgeon's center denies transplants for patients involves psychosocial criteria. Although the surgeon's hospital has general guidelines for the use of psychosocial factors that help with objective evaluation of individuals, the surgeon stressed that, ultimately, each surgeon must use an internal compass to decide whether a person is psychosocially qualified. The surgeon also expressed much more reluctance at putting an individual with severe mental disabilities on the waitlist as opposed to putting an individual with a moderate case on the list due to general concerns that the individual will be less likely to comply and, therefore, waste an organ. The surgeon, however, could not specify the differences between severe and moderate cases. Although the surgeon disavowed using social worth criteria when evaluating the eligibility of an individual with mental disability for placement on the waitlist, the surgeon's explanation of how psychosocial factors affect eligibility appeared to use them, if unconsciously, as proxies for social worth determinations. When asked why performing a transplant on a young child is considered preferable than doing so in a person with a mental disability—since both are usually legally incompetent and will need familial or other support to ensure compliance—the surgeon responded that the child would likely have future independence, whereas the person with a mental disability would end up as a state ward. This is despite the fact that the surgeon also stated that children can be some of the most difficult compliance cases because once they hit adolescence, they often do not want to comply with their postsurgical treatment. The surgeon also clearly indicated that a child without mental disability would be a preferable candidate for transplantation in comparison to an individual with a mental disability, all other aspects equal.

compliance often takes into account an individual's independence.⁵³ Selection of this factor could easily be a social worth determination because a high percentage of individuals with mental disabilities are not independent, unlike most individuals as they grow into adulthood; in their case, the likelihood of dependence may require expending private and public resources to ensure compliance. Arguments respecting the devotion of such resources has been understood broadly as a matter of social worth in its utilitarian sense. For individuals with mental disabilities, additional support is not only expected to be necessary, but it also can be affirmatively required through the ADA or state law counterparts.⁵⁴ Thus, if the criterion does not provide clear compliance exceptions for individuals who have adequate support systems—essentially, to take the place of independence—then it runs the risk that the general population will be favored over individuals with mental disabilities without medical justification. The risk occurs because, although independence may support compliance, it is not the only way an individual can achieve it. For example, people can achieve compliance with the support of others, which is recognized in California Health and Safety Code section 7151.35(c): “A person with a physical or mental disability shall not be required to demonstrate postoperative independent living abilities in order to have access to a transplant if there is evidence that the person will have sufficient, compensatory support and assistance.”⁵⁵ Thus, if compliance and competence are used as factors to consider an individual's risk of creating waste, it must be done carefully and consciously to avoid unfair treatment.

III. CURRENT TRANSPLANTATION LAW AND POLICIES

To understand fully how mental disability affects an individual's eligibility for transplantation, one must first review the laws and regulations surrounding organ transplantation and how these laws interact with disability law. For many years, there were no laws governing transplantation and organ donation, causing uncertainty and, in the minds of many, unfair and preferential results. In response, over the span of approximately forty years, the legal and medical communities, with input

53. Social worth criteria are morally relevant because they implicitly suggest that it is morally better to favor the people who are independent based on the person's likelihood of surviving and thriving being greater than people who are dependent, and that increased likelihood makes the independent person more meritorious than the dependent person.

54. See *infra* Part III.E.2 (discussing ADA reasonable accommodations in the transplantation process).

55. CAL. HEALTH & SAFETY CODE § 7151.35(c) (West Supp. 2013). See also *infra* Part V.A (discussing California's antisability transplantation discrimination law).

from the general public, created the Uniform Anatomical Gift Act to provide guidance to states regarding their donation policies. Additionally, Congress enacted NOTA to regulate the organ allocation process, and HHS promulgated rules to support UNOS's administration of the OPTN established under NOTA. These rules, however, do not provide guidance for the initial evaluation stage of the transplant waitlist eligibility process, nor do they specify how to evaluate individuals with mental disabilities. Therefore, they must be analyzed in conjunction with the ADA to determine whether using psychosocial criteria to evaluate individuals with mental disabilities withstands statutory protections provided to such individuals.

A. UNIFORM ANATOMICAL GIFT ACT: GUIDANCE FOR ORGAN DONATION AND THE DETERMINATION OF DEATH

In 1968, the National Conference of Commissioners on Uniform State Laws ("NCCUSL")⁵⁶ created the Uniform Anatomical Gift Act ("UAGA")—the first law on organ transplantation—as a model for states to create uniform laws regarding organ donation.⁵⁷ By 1973, the act had been passed by every state in varying form.⁵⁸ The UAGA specifies that "[a]ny individual of sound mind and 18 years of age or more may give all or any part of his body for any purpose . . . , the gift to take effect upon death."⁵⁹ Additionally, if the decedent does not specify his donation preferences prior to death, the UAGA provides, in descending order of authority, who may permit donation of all or some of the decedent's body. The act also specifies that organ or bodily donations can be made to hospitals, surgeons, physicians, researchers, institutes of higher education, storage facilities for transplantation, or specific individuals for transplantation.⁶⁰ The 1980 version of the UAGA added a definition of brain death to the act, which was intended to increase the availability of

56. See *About the ULC*, UNIF. LAW COMM'N, [http://www.uniformlaws.org/Narrative.aspx?title=About the ULC](http://www.uniformlaws.org/Narrative.aspx?title=About%20the%20ULC) (last visited Nov. 9, 2013) (explaining that the NCCUSL is comprised of lawyers across the nation who work to propose uniform laws for the states).

57. Jacqueline Zee, *The Revised Uniform Anatomical Gift Act: Bringing "California Donation Law Up to Contemporary Medical, Legal, and Bioethical Practices"*, 39 MCGEORGE L. REV. 529, 533–34 (2008).

58. *Id.* See also U.S. Dep't Health & Human Servs., *State Organ Donation Legislation*, ORGANDONOR.GOV, http://www.organdonor.gov/legislation_micro/ (last updated Jan. 2011) (providing additional information on each state's anatomical gift act).

59. UNIF. ANATOMICAL GIFT ACT § 2(a) (1968), available at http://www.uniformlaws.org/shared/docs/anatomical_gift/uaga%201968_scan.pdf.

60. *Id.* § 3.

viable organs for transplantation. Under the common law, death occurs with the cessation of breathing and circulation of blood.⁶¹ This definition, however, is unworkable in the context of transplantation because “[i]n order for organs to be viable for transplantation, both circulation and respiration must be maintained in the host body.”⁶² To remedy this definitional problem, the UAGA provides brain death as a second standard for determining death in order to better support transplantation procedures.⁶³

In 2006, the NCCUSL updated the UAGA to favor transplantation over research when the donor indicates intent to donate, but does not specify to whom,⁶⁴ and “grants broad good faith immunities for nearly everyone involved in the organ procurement process.”⁶⁵ Currently, forty-five states have enacted the 2006 version of the UAGA.⁶⁶

B. NATIONAL ORGAN TRANSPLANT ACT: REGULATING THE ALLOCATION PROCESS

As transplantation became a more mainstream procedure throughout the 1960s and 1970s, public concern increased regarding unfairness and inequities in the transplantation system.⁶⁷ Congress reacted by enacting NOTA in 1984, which created a national organ transplantation policy.⁶⁸ NOTA required HHS to establish the OPTN, which is responsible for creating and overseeing national allocation policies, as well as the computerized national registry of patients eligible for transplantation.⁶⁹ The

61. UNIF. DETERMINATION OF DEATH ACT § 1 (1980), reprinted in MICHAEL H. SHAPIRO ET AL., *BIOETHICS AND LAW* 945 (2d ed. 2003).

62. Fred H. Cate, *Human Organ Transplantation: The Role of Law*, 20 J. CORP. L. 69, 74 (1994).

63. *Id.* at 74–75 (defining “[a]n individual who has sustained . . . irreversible cessation of all functions of the entire brain, including the brain stem” as dead).

64. *Anatomical Gift Act (2006) Summary*, UNIF. LAW COMM’N (2013), [http://www.uniformlaws.org/ActSummary.aspx?title=Anatomical Gift Act \(2006\)](http://www.uniformlaws.org/ActSummary.aspx?title=Anatomical%20Gift%20Act%20(2006)).

65. Brian Morris, Note, *You’ve Got to Be Kidneying Me! The Fatal Problem of Severing Rights and Remedies from the Body of Organ Donation Law*, 74 BROOK. L. REV. 543, 551 (2009).

66. See *Legislative Fact Sheet—Anatomical Gift Act (2006)*, UNIF. LAW COMM’N (2013), [http://www.uniformlaws.org/LegislativeFactSheet.aspx?title=Anatomical%20Gift%20Act%20\(2006\)](http://www.uniformlaws.org/LegislativeFactSheet.aspx?title=Anatomical%20Gift%20Act%20(2006)) (listing those states that have enacted the 2006 UAGA); *Anatomical Gift Act (2006)—Enactment Status Map*, UNIF. LAW COMM’N (2013), [http://www.uniformlaws.org/Act.aspx?title=Anatomical%20Gift%20Act%20\(2006\)](http://www.uniformlaws.org/Act.aspx?title=Anatomical%20Gift%20Act%20(2006)) (showing that Delaware, Florida, Illinois, New York, and Pennsylvania have not yet enacted the 2006 UAGA, but have introduced legislation to do so).

67. See, e.g., Dulcinea A. Grantham, *Transforming Transplantation: The Effect of the Health and Human Services Final Rule on the Organ Allocation System*, 35 U.S.F. L. REV. 751, 774 (2001) (noting the possibility that nonmedical factors, such as fame, can effect an individual’s likelihood of receiving a transplant).

68. See National Organ Transplant Act, 42 U.S.C. §§ 273–274g (2006).

69. See *id.* § 274(b)(2) (describing that the OPTN’s waitlist registry matches and ranks available

OPTN is also tasked with “carry[ing] out studies and demonstration projects for the purpose of improving procedures for organ donation procurement and allocation, including . . . projects to examine and attempt to increase transplantation among populations with special needs.”⁷⁰ Rather than delegating the management of the OPTN to HHS, NOTA requires the HHS Secretary to contract with “a private nonprofit entity that has an expertise in organ procurement and transplantation.”⁷¹ UNOS has filled this role since 1986. In its capacity as the OPTN administrator, UNOS is responsible for “establish[ing] . . . medical criteria for allocating organs” within the network,⁷² as well as assisting organ procurement organizations (“OPOs”) in coordinating the allocation and transportation of organs. There are fifty-eight OPOs spread out over eleven geographic regions.⁷³ Generally, organs that become available are first offered to the OPO’s local territory, then within its geographic region, and finally nationally.⁷⁴ The geographic priorities promote organ preservation, which limits wastage, and local autonomy.

C. HEALTH AND HUMAN SERVICES’ FINAL RULE: GUIDANCE FOR OPTN OPERATION AND ALLOCATION POLICIES

In 1998, HHS released regulations for the operation of the OPTN (“Final Rule”).⁷⁵ The Final Rule mandates that the OPTN Board of Directors develop “[p]olicies for the equitable allocation of cadaveric organs” and submit them for approval to the HHS Secretary.⁷⁶ Specifically, the OPTN’s allocation policies must be based on

- (1) “sound medical judgment,”
- (2) “the best use of donated organs,”
- (3) “avoid[ing] wasting organs . . . [and] futile transplants,”

organs with appropriate patients “in accordance with established medical criteria”).

70. *Id.* § 274(b)(2)(N).

71. *Id.* § 274(b)(1)(A).

72. *Id.* § 274(b)(2)(B).

73. *About OPOs*, ASS’N OF ORGAN PROCUREMENT ORGS. (2010–2011), <http://www.aopo.org/about-opo>; *Members/Regions*, ORGAN PROCUREMENT TRANSPLANTATION NETWORK, <http://optn.transplant.hrsa.gov/members/regions.asp> (last visited Nov. 20, 2013).

74. *See infra* Part III.C (giving a more complete description of organ allocation policies).

75. The Final Rule requirements listed here do not represent the entire rule, but these sections are those most related to the process of physician evaluation of patients and to the allocation process generally.

76. OPTN Final Rule, 42 C.F.R. § 121.4(a)(1) (2013). *See also id.* § 121.4(b)(2) (stating that “[t]hese policies will not be enforceable until approved by the Secretary. . . . [and that] [i]f the Secretary concludes that a proposed policy is inconsistent with the National Organ Transplant Act or this part, the Secretary may direct the OPTN to revise the proposed policy consistent with the Secretary’s direction.”).

- (4) “promot[ing] patient access to transplantation,” and
- (5) “promot[ing] the efficient management of organ placement.”⁷⁷

The OPTN also must have procedures in place to review “each transplant program’s application of the policies to patients . . . proposed to be listed at the program.”⁷⁸ To determine whether the OPTN’s policies result in equitable allocation, HHS looks at the following:

- (1) the standardization of “objective and measurable medical criteria[] for adding individuals to . . . organ transplant waiting lists,”
- (2) the creation of “priority rankings . . . [based on] objective and measurable medical criteria . . . ordered from most to least medically urgent . . . in accordance with sound medical judgment,”
- (3) the distribution of “organs over as broad a geographic area as feasible,” and
- (4) the application of “appropriate performance indicators to assess transplant program performance.”⁷⁹

Under the final factor, one performance indicator is “data regarding . . . patients who were inappropriately kept off a waiting list.”⁸⁰ Additionally, for a transplant center to be eligible to receive organs for transplantation, it must “[m]ake[] available psychiatric and social support services for transplant candidates, transplant recipients, and their families.”⁸¹ This section is particularly intriguing, as it could provide UNOS with authority to regulate psychosocial criteria and the initial evaluation process; however, the regulation has yet to be interpreted in this light and UNOS has not created policies that would test its authority to do so. Additionally, this provision, when considered in combination with the ADA, may create affirmative obligations on transplant centers to provide additional support to individuals with mental disabilities.⁸²

D. OPTN ALLOCATION POLICIES: ESTABLISHING RANKING AND DISTRIBUTION CRITERIA FOR PATIENTS ONCE ON A WAITLIST

The current regulatory scheme under NOTA and HHS’s Final Rule attempts to address distributive justice issues in the allocation stage of the

77. *Id.* § 121.8(a). These goals sometimes work together and at other times work against each other. Thus, OPTN must try to create policies that maximize all of these goals, but this ultimately will be an imperfect solution.

78. *Id.* § 121.8(a)(7).

79. *Id.* § 121.8(b).

80. *Id.* § 121.8(c)(3).

81. *Id.* § 121.9(a)(2)(vii).

82. See *infra* Part III.E.2 (discussing ADA reasonable accommodations and affirmative obligations).

transplantation process by mandating that the OPTN's policies be based on sound medical judgment, objective medical criteria, and medical urgency. This formula is designed to achieve the overall purposes of allocating organs for their best use and avoiding wastage. Below are summaries of the OPTN's organ-specific allocation policies for kidneys, livers, and hearts.

1. Kidney Allocation Policies: No Consideration of Medical Urgency

For kidneys, the OPTN groups candidates based on their blood type and blood antigens.⁸³ O donor organs must be given to O donees, and B donors to B donees, unless there is a zero antigen mismatch.⁸⁴ An individual's length of time waiting on the list is prioritized,⁸⁵ but medical urgency is not.⁸⁶ For candidates who are not zero antigen mismatched, priority is based on descending percentages of compatibility. Additionally, candidates who previously donated a kidney are given priority.⁸⁷ When a kidney becomes available, candidates are listed as local, regional, or national, depending on their distance from the donor organ.⁸⁸ There are ten priority categories with highest priority given to identical blood type, zero antigen mismatched, local candidates, and then generally in descending order of blood and antigen mismatch, rotating in preference of local, then regional, and finally national candidates.⁸⁹

2. Liver Allocation Policies: Allocation Based on Medical Urgency, Blood and Size Compatibility, Waiting Time, and Distance from the Donor Organ

For livers, the OPTN groups individuals on the waitlist by their blood type and the size of liver needed.⁹⁰ Then, the qualified individuals are ranked by medical urgency and time on the waitlist at that urgency level.⁹¹ Medical urgency is determined by an individual's numerical Model for

83. OPTN KIDNEY POLICY, *supra* note 21, § 3.5.5.5. See also U.S. Nat'l Library of Med., *Antigen Definition*, MEDLINEPLUS, <http://www.nlm.nih.gov/medlineplus/ency/article/002224.htm> (last updated Aug. 30, 2012) (defining an antigen as "any substance that causes your immune system to produce antibodies against it").

84. See OPTN KIDNEY POLICY, *supra* note 21, § 3.5.5.5 (explaining that a candidate is considered to be a zero antigen mismatch when he has a compatible blood type with the donor and has all of the same six antigens considered for transplantation).

85. *Id.* § 3.5.4.

86. *Id.* § 3.5.11.4. Urgency is not prioritized in the same way as it is for hearts or livers because of the widespread availability and effectiveness of kidney dialysis.

87. *Id.* § 3.5.11.6.

88. *Id.* § 3.5.6.

89. *Id.* tbl.3.5-5.

90. OPTN LIVER POLICY, *supra* note 21, § 3.5.5.5.

91. *Id.* §§ 3.6.3-4.

End-Stage Liver Disease (“MELD”) score.⁹² In addition to these scores, there are two categories, 1A and 1B, reserved for the most medically needy.⁹³ Lastly, the candidates for a specific available liver are listed as being local, regional, or national. A local candidate is one within the same OPO as the donated organ. A regional candidate is one within the same OPTN defined region as the donor organ.⁹⁴ A national candidate is one outside the donor liver’s region.⁹⁵ Based on these factors, there are thirteen priority categories with local and regional 1A and 1B candidates ranked highest and the remaining eleven categories generally listed by descending MELD score and time on the waitlist at that score and rotated through local, regional, and national candidates, in that order.

3. Heart Allocation Policies: Allocation Based on Medical Urgency, Wait Time, Blood Type, and Distance from the Donor Organ

Heart candidates are assigned a status code corresponding with their medical urgency (1A, 1B, and 2, in descending order of urgency).⁹⁶ Within each status code, candidates are ranked higher based on time on the waitlist at that status level.⁹⁷ When a donor heart becomes available, candidates are categorized by compatible blood types of the donor organ within each status category.⁹⁸ Unlike livers, hearts are allocated geographically first to the local OPO area and then within concentric circles emanating from the transplant center with distances of 500, 1000, 1500, 2500, and 2500+ nautical miles for each circle and with closer circles prioritized over farther ones.⁹⁹ There are eighteen prioritization categories that rotate generally by geographical distance and status level with prioritization given to the

92. See UNITED NETWORK FOR ORGAN SHARING, TALKING ABOUT TRANSPLANTATION: QUESTIONS & ANSWERS FOR TRANSPLANT CANDIDATES ABOUT LIVER ALLOCATION POLICY 1 [hereinafter TALKING ABOUT TRANSPLANTATION], available at http://www.unos.org/docs/Liver_patient.pdf (explaining that MELD scores are based on a numerical scale of six to forty; the lower the numerical score, the less ill the individual is in terms of survival time without transplantation). For the purposes of this analysis, pediatric PELD scores are not analyzed.

93. *Id.*

94. See *supra* Part III.B (discussing the geographic distribution system created by NOTA).

95. TALKING ABOUT TRANSPLANTATION, *supra* note 92, at 2–3.

96. ORGAN PROCUREMENT & TRANSPLANTATION NETWORK, ORGAN DISTRIBUTION: ALLOCATION OF THORACIC ORGANS § 3.7.3 (2013) [hereinafter OPTN THORACIC POLICY], available at http://optn.transplant.hrsa.gov/PoliciesandBylaws2/policies/pdfs/policy_9.pdf.

97. *Id.* § 3.7.9.

98. *Id.* § 3.7.8.i–iv (establishing that O can give to O or B, B can give to B or AB, A can give to A or AB, and AB can give to AB only. If no suitable donee is found within these categories, and if the donor heart is an O, candidates with A or AB blood types will then be considered based on medical urgency).

99. *Id.* § 3.7.2.

greatest need and closest distance.¹⁰⁰

4. Status 7 Candidates

For organ allocation policies in which candidates are ranked by medical urgency and time on the waitlist, there is an additional status category, Status 7, for candidates who are “temporarily unsuitable” for transplantation because their health is too precarious to be likely to survive the transplantation surgery.¹⁰¹ These candidates are considered inactive because they cannot meet the medical requirements to undergo surgery and, therefore, are not ranked for available organs. The benefit of this category is that it allows candidates to remain on the waitlist, which retains the time they have accrued while active on the waitlist, but they do not accrue time while categorized as Status 7 because they cannot medically receive a transplant during that period.¹⁰²

E. AMERICANS WITH DISABILITIES ACT: PROHIBITING DISCRIMINATION IN THE ACCESS OF HEALTH CARE

With the enactment of the ADA in 1990, Congress sought to eliminate both intentional and general societal discrimination against individuals with disabilities through specific prohibitions and affirmative obligations on public and private programs and services, explicitly noting that disability discrimination is a “serious and pervasive social problem . . . persist[ing] in such critical areas as . . . health services.”¹⁰³ Under the ADA, an individual is considered disabled if he has “a physical or mental impairment that substantially limits one or more . . . major life activit[y],” has “a record of such an impairment,” or is “regarded as having such an impairment.”¹⁰⁴

100. *Id.* § 3.7.10.

101. *Id.* § 3.7.3; OPTN LIVER POLICY, *supra* note 21, § 3.6.4.1.

102. OPTN THORACIC POLICY, *supra* note 96, § 3.7.9.

103. Americans with Disabilities Act, 42 U.S.C. § 12101 (2006). *See also* Andrew Altman, *Discrimination*, STANFORD ENCYCLOPEDIA OF PHIL. (Feb. 1, 2011), <http://plato.stanford.edu/entries/discrimination/#ConDis> (arguing that legal discrimination requires wrongfulness, but simply distinguishing between candidates, without the specific purpose to disadvantage one over the other, may result in disadvantages to one group over another, but is not necessarily wrongful discrimination).

104. 42 U.S.C. § 12102(1) (Supp. 2011). Determining what level of impairment constitutes a substantially limiting disability is a fluid process without clear boundaries. In the context of transplantation, this is especially difficult because of the scarcity issue. Different degrees of scarcity may require different understandings of what constitutes unacceptable discrimination; the greater the scarcity, the more distinctions must be drawn. This issue is compounded by the fact that although the ADA and other laws provide for affirmative support for such individuals, they are not as comprehensive in reality as the law may suggest that they should be. Thus, the law clashes if someone meets the substantial limitation threshold and yet does not have sufficient support (individually, familial, or otherwise) to tend to postoperative care. The ADA may require additional support, but this may be

Major life activities are defined broadly, such as “caring for oneself, . . . learning, . . . concentrating, thinking, communicating, and working,” but they can also be as basic as “eating, sleeping . . . [and] breathing.”¹⁰⁵ Such activities are substantially limited if an individual cannot perform these functions at a similar level as the general population.¹⁰⁶ If an individual falls within the ADA disability definition and meets the essential eligibility requirements of a program or service, with or without accommodation, he is considered a qualified individual and cannot be discriminated against based on his disability.¹⁰⁷ If qualified, the individual is entitled to a reasonable accommodation in accessing services because

if we prohibited discrimination only when disabilities had no effect on a person’s functioning, we would do nothing to counteract the fact that our social structures are inherently biased against persons with disabilities. Treating people with disabilities equally when they start out with an unfair disadvantage simply perpetuates the original disadvantage. Thus, the principle of reasonable accommodations requires that reasonable steps be taken to counteract the inherent biases of social structure.¹⁰⁸

These accommodations are modifications or adjustments that enable the individual to participate in the program, service, or activity.

The obligations of health care providers and hospitals are covered under Title III (private entities) of the ADA,¹⁰⁹ providing that these entities cannot “subject an individual or class of individuals on the basis of a disability . . . to a denial of the opportunity of the individual or class to participate in or benefit from the goods, services, facilities, privileges, advantages, or accommodations of an entity.”¹¹⁰ Additionally, if a hospital is affiliated with a state or local government or with a state university, it may be considered a public entity under Title II of the ADA, which has the same requirements as Title III, only implemented through regulations by the Department of Justice.¹¹¹ It also renders them subject to constitutional

difficult to receive in reality (due to budget cuts in In Home Supportive Services, and so forth), which in turn may cause a center to deny transplantation for the patient.

105. *Id.* § 12102(2).

106. Shawn Kravich, Associate Director, Cancer Legal Resource Center, Presentation: Americans with Disabilities Act Titles II and III (June 1, 2012) (slides on file with author).

107. 42 U.S.C. §§ 12111(g), 12102(2) (2006).

108. Orentlicher, *supra* note 8, at 64.

109. 42 U.S.C. § 12181(6).

110. *Id.* § 12182(b)(1)(A)(i).

111. *Id.* § 12131(1); 28 C.F.R. § 35.130 (2013) (finding a hospital or physician to be a state actor is important for the purposes of bringing constitutional discrimination challenges under the Fourteenth Amendment).

constraints, but this sphere is outside the scope of this Note.¹¹² It is not clear, however, whether UNOS should be considered a government entity, despite its description as a private entity.¹¹³ A health care provider or hospital discriminates against individuals with disabilities by (1) imposing or applying “eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities,” or (2) failing “to make reasonable modifications in policies, practices, or procedures, when such modifications are necessary to afford such goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities.”¹¹⁴

1. Evaluating Transplantation Eligibility Criteria Under the Americans with Disabilities Act

Since the passage of the ADA, there has been minimal discussion regarding what the act requires of transplantation centers when creating initial evaluation criteria, evaluating patients with mental disabilities for placement on a transplantation waitlist, or when determining reasonable modifications to their eligibility policies to facilitate waitlist eligibility and, eventually, successful transplantation. Today, many medical centers still view mental disability as a predetermined relative or absolute contraindication to long-term transplantation success—especially for hearts and livers—even though there has been a significant decline in these policies.¹¹⁵ As suggested in Part II, if individuals with mental disabilities have similar compliance and survival rates post-transplantation and, therefore, meet a “minimum threshold of benefit” similar to the general population, using mental disability as a contraindication to transplantation

112. It is questionable whether an individual with a mental disability who is improperly treated during the transplantation process would be able to make a constitutional discrimination claim against private hospitals and their physicians, as would be possible for improper treatment at a public hospital. *See generally* *Wheat v. Mass*, 994 F.2d 273, 275–76 (5th Cir. 1993) (suggesting that private hospitals and their physicians are not state actors under the Fourteenth Amendment “solely because [they] receive[] medicare and medicaid fund[ing] and [are] subject to state regulation” and are not federal actors under the Fifth Amendment by “recei[ving] federal funds by virtue of [their] participation in UNOS”).

113. *See* Benjamin Mintz, Note, *Analyzing the OPTN Under the State Action Doctrine—Can UNOS’s Organ Allocation Criteria Survive Strict Scrutiny?*, 28 COLUM. J.L. & SOC. PROBS. 339, 356–76 (1995) (arguing that UNOS, a private nonprofit organization, should be considered a state actor under the coercion theory, which occurs when “incidents of governmental authority” compel action of a private party, because its contract with HHS to administer the OPTN “legally require[s] it] to implement” national policies).

114. 42 U.S.C. § 12182(b)(2)(A).

115. *See supra* Part III.A.2 (discussing surveys of transplantation centers’ policies considering mental disability as an absolute or relative contraindication to long-term transplantation success).

likely violates the ADA's prohibition on holding qualified individuals with disabilities to a higher standard than the general population.¹¹⁶ Thus, establishing hospital policies that list mental disability as an automatic contraindication may be "designed as subterfuge[] to evade the purposes of the ADA."¹¹⁷

This does not mean, however, that mental disability can never be taken into account—it just should be considered only after individual evaluation of a patient. This is consistent with how the general population is evaluated—without presumption of contraindications to transplantation—and would help ensure that individuals with mental disabilities are not held to a higher standard than others are held to in order to obtain lifesaving treatment. Orentlicher explains bona fide considerations versus subterfuge in the transplantation process as

when an organ transplant program denies organs on the basis of sickness or based on criteria that screen out sicker persons, the program could justify its decisions in terms of traditional risk classification practices. If patients have sicknesses that compromise their ability to benefit from organ donation, then transplant program administrators could argue that it does not make sense to give such patients the same priority on the organ transplantation list as persons who would gain a greater benefit.¹¹⁸

Thus, if the center has a bona fide reason for using mental disability as an eligibility factor for a specific individual, such as if there is actual evidence that the person's mental disability will affect his ability to comply, mental disability can be considered. Nevertheless, even if there are legitimate compliance issues that are a result of the individual's mental disability, if the person otherwise would qualify for transplantation, the hospital and physician may have affirmative obligations to accommodate the individual to support access to transplantation.

2. Reasonable Accommodations in the Transplantation Process: Compliance and Outside Support

Qualified individuals with mental disabilities may have additional rights to reasonable accommodations to "ensure access to a transplant."¹¹⁹ Orentlicher asserts that, in the context of transplantation,

116. Samelson-Jones, Mancini & Shapiro, *supra* note 30, at 137.

117. Orentlicher, *supra* note 8, at 57. *See also* Martens, Jones & Reiss, *supra* note 31, at 660 (stating that "[p]resently, there is little scientific data demonstrating poor outcomes or medical complications following organ transplantation in individuals with [mental disabilities]").

118. Orentlicher, *supra* note 8, at 57–58.

119. Samelson-Jones, Mancini & Shapiro, *supra* note 30, at 137.

organ recipients have many responsibilities to ensure survival of their organs. Those responsibilities might not be feasible for a disabled person alone, but they might become feasible if the organ transplant program provided support services. Some transplant centers have been able to overcome compliance problems by having frequent contact with their patients. If interpreted as it has been in non-medical contexts, reasonable accommodations would likely require the provision of these support services as long as it would not be unduly burdensome for the transplant program to do so.¹²⁰

Nevertheless, if the entity can show that the modification would fundamentally alter or overburden the service, it would not be considered reasonable and, therefore, would not be required under the ADA.¹²¹ Hence, an unreasonable accommodation would be prohibitively costly or would not provide the individual with “a reasonable minimum level of benefit from treatment.”¹²² Determining the minimum benefit, however, would likely still fall into the realm of physician discretion, which again creates the possibility that social worth will improperly factor into the decisionmaking process. This is why uniform federal policies are needed in the transplantation eligibility process. Evidence that individuals with mental disabilities can meaningfully comply with or without assistance at similar rates to the general population and that they have positive survival outcomes means that transplant centers likely are affirmatively obligated to provide additional compliance services to individuals with mental disabilities so that they are eligible for transplantation.

IV. ALLEGATIONS OF UNFAIR TREATMENT OF INDIVIDUALS WITH MENTAL DISABILITIES

In the past year, the media have highlighted two instances of possible unfair treatment of individuals with mental disabilities in the transplantation process. Their experiences, viewed retrospectively with Sandra Jensen’s experience of disability discrimination in the 1990s, indicate that the possibility for mental disability discrimination is a serious, continuing problem. The fact that these cases continue to arise with few means of formal redress indicates that there may be serious problems with how the current transplantation process evaluates the candidacy of

120. Orentlicher, *supra* note 8, at 66.

121. 42 U.S.C. § 12111(9), (10) (2006). *Cf.* PGA Tour, Inc. v. Martin, 532 U.S. 661, 690 (2001) (holding that allowing a disabled golfer to ride instead of walk the golf course during tournaments was not a fundamental alteration of golf tournaments and, therefore, was a reasonable modification required by the ADA).

122. Orentlicher, *supra* note 8, at 72.

individuals with mental disabilities for transplantation.

A. PAUL CORBY: AUTISM AND THE DENIAL OF ACCESS TO THE HEART
TRANSPLANT WAITLIST

In 2008, Paul Corby, then nineteen years old, was diagnosed with a congenital heart defect in his left ventricle that causes his heart to pump blood at approximately 20 percent efficiency.¹²³ Corby also has autism¹²⁴ and a mood disorder that causes “occasional outbursts,”¹²⁵ which are unrelated to his heart condition. After surviving three mini-strokes, Corby’s heart condition became serious enough for his doctors to consider transplantation. In June 2011, however, Corby’s cardiologist at the Penn Transplant Institute (affiliated with the University of Pennsylvania) in Philadelphia denied him access to the national heart transplantation waitlist because of his “psychiatric issues [referring to his mood disorder], autism, the complexity of the process, multiple procedures and the unknown and unpredictable effect of steroids [used for anti-rejection purposes] on behavior.”¹²⁶

According to Corby’s mother, Karen Corby, the cardiologist’s evaluation of her son was amiss: “The doctor was more interested in the fact that he could not name all his medications (he takes 19 at the present time) and the Princess Peach doll he carries for comfort, . . . than the fact that he has never smoked or drank alcohol.”¹²⁷ She also asserts that the transplant center “never performed any tests to evaluate Paul’s heart condition or mental status.”¹²⁸ Corby’s mother is not alone in her concern that her son is being rejected unfairly based on his mental disability. Dr. Dan Coury, medical director for Autism Speaks, voiced his concern that the hospital may have looked at Corby “as a label rather than the unique

123. Thomas Leskin, *Heart Transplant Fight Continues for Pottsville Man*, REPUBLICAN HERALD (Oct. 28, 2012), <http://republicanherald.com/news/heart-transplant-fight-continues-for-pottsville-man-1.1395080>; Lou Melgarejo, *Thoughts on Paul Corby*, HUFFINGTON POST: THE BLOG (Aug. 22, 2012, 5:43 PM), http://www.huffingtonpost.com/lou-melgarejo/paul-corby-transplant_b_1823073.html.

124. Leskin, *supra* note 123 (noting that Corby has been diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified, which is an autism spectrum disorder).

125. Ryan Jaslow, *23-Year-Old Denied Transplant by U Penn Hospital Because of Autism, Mom Says*, CBS NEWS (Aug. 17, 2012, 4:59 PM), http://www.cbsnews.com/8301-504763_162-57495692-10391704/23-year-old-denied-heart-transplant-by-u-penn-hospital-because-of-autism-mom-says/.

126. Letter from Paul Corby’s cardiologist, Penn Medicine at Radnor, to Karen Corby (June 13, 2011) (on file with author).

127. Karen Corby, *Help My Autistic Son Get A Lifesaving Heart Transplant*, CHANGE.ORG PETITION, <http://www.change.org/petitions/help-my-autistic-son-get-a-life-saving-heart-transplant> (last visited Sept. 20, 2013).

128. *Id.*

qualities” that he possesses.¹²⁹

In response to the Corbys’ protests and public concern, the Penn Transplant Institute has been vague, at best, in explaining its decision to deny Corby access to the waitlist. The hospital has stated that it cannot discuss Corby’s case specifically (even though his mother has given the hospital permission to do so), but asserts that

when individuals are referred for transplant consideration at Penn . . . all aspects of their medical status [are] reviewed. . . . This includes the current health status and post-transplant prognosis of the recipient, the impact of other existing health problems on the success of the surgery itself and over the longer term, as well as the potential interaction between a patient’s existing drug therapies and the drugs that would be necessary to stop transplant rejection.¹³⁰

The possibility that Corby was denied access to the waitlist primarily because of his autism is troubling. Now twenty-three years old, Corby is considered high functioning. He can carry on a conversation, enjoys playing video games, and has written a self-published novel.¹³¹ He also has familial support from his mother, older sister, four aunts, and two uncles.¹³² Importantly, Corby also understands the seriousness of his condition. When asked about his denial, Corby responded that he is “not too thrilled about it” and stressed that he wants “[the doctors] to know how [he] feels. . . . That [he] want[s] a heart transplant.”¹³³ Corby’s psychiatrist, Dr. Newton, corroborated, stating “[h]e is very much aware of the severity of his medical condition and this has been playing on his mind. Nonetheless he continues to hold himself well.”¹³⁴ Based on the above facts, Dr. Arthur Caplan, head of the Division of Medical Ethics at New York University’s Langone Medical Center, has commented that individuals like Corby—those with positive outlooks on life and strong familial support—are not

129. Sydney Lupkin, *Autism Transplant Denial Sparks Debate*, ABC NEWS (Aug. 15, 2012), <http://abcnews.go.com/Health/autistic-man-denied-heart-transplant-upenn-hospital/story?id=17006152>.

130. Matt Moore & Kevin Begos, *Mom Seeks Heart Transplant for Autistic Son*, ASSOCIATED PRESS (Aug. 17, 2012), available at <http://www.washingtontimes.com/news/2012/aug/17/mom-seeks-heart-transplant-for-autistic-son/?page=all> (statement from Penn Hospital spokesperson Susan Phillips).

131. *Should an Autistic Man Be Denied a Heart Transplant?*, THE WEEK (Aug. 16, 2012), <http://theweek.com/article/index/232120/should-an-autistic-man-be-denied-a-heart-transplant>.

132. Joslyn Gray, *Young Man Denied Heart Transplant—His Autism May Be the Reason*, BABBLE (Aug. 7, 2012, 5:57 PM), <http://blogs.babble.com/strollerderby/2012/08/07/family-young-man-denied-heart-transplant-because-hes-autistic/>.

133. *Id.*

134. Letter from Andrew O. Newton, Psychiatrist, to Paul Corby’s cardiologist, Penn Medicine at Radnor (April 28, 2011) (on file with author).

justifiably denied lifesaving treatment.¹³⁵

Admittedly, Corby's transplant—like all transplants—entails complex procedures and a lifetime of medical intervention. However, since he is high functioning, understands the severity of his medical condition, and has a strong network of familial support, it is difficult to see how his “autism, the complexity of the process, [or the] multiple procedures” increased his chances of an unsuccessful heart transplant over that of similarly situated nonautistic persons. This leaves his mood disorder and the “unpredictable effect of steroids [used for antirejection treatment] on behavior” as the remaining justifications for his denial. In this case, then, the denial may reflect a subtext for social worth bias against individuals with mental disabilities. Nevertheless, Dr. Newton asserts that although Corby takes a plethora of medications, “he remains clinically stable and he [has been] complian[t] with all aspects of [his] psychiatric care and medication management.”¹³⁶ Moreover, autism advocates stress that mood disorders are common in individuals with autism, suggesting that the physician may be double weighing his mental disability.¹³⁷ Based on the above, Dr. Newton has determined that “[f]rom the [p]sychiatric point of view there is no clinical reason why he would not benefit from cardiac transplant . . . [and] recommend[ed] him without any reservations for heart transplant all other parameters being stable.”¹³⁸ Although the physician's concerns about Corby's anger control are legitimate, as it could affect his compliance with postoperative treatment, steroids affect an individual's behavior regardless of whether they have autism. With this in mind, Corby is no different from the general population. Additionally, there are medications that may limit the effects of steroids on behavior that Dr. Newton is willing to prescribe should Corby's behavior become a problem on the anti-rejection steroids.¹³⁹ In this light, it seems that there are few, if any, medical or psychosocial reasons to deny Corby a place on the waitlist.

Two additional facts in the Corby case may further suggest that his denial was not medically justified. First, the Penn Medicine transplant team has previously performed a heart transplant on a person with autism,¹⁴⁰

135. Jaslow, *supra* note 125.

136. Newton, *supra* note 134.

137. Gray, *supra* note 132.

138. Newton, *supra* note 134.

139. Gray, *supra* note 132. There is no information provided on the specific medication that could be prescribed to counteract the side effects of the steroids.

140. Stacey Burling, *Claim: Heart Transplant Denied Due to Man's Autism*, PHILA. INQUIRER (Aug. 14, 2012), <http://www.disabilitycoop.com/2012/08/14/claim-heart-transplant-autism/16251/>. There is no information provided on whether the other individual was higher functioning than Corby.

indicating that the center may not treat individuals with mental disabilities unfairly as a class. This does not mean, however, that Corby was not discriminated against as an individual, especially since it is not clear if the same cardiologist recommended the other individual with autism for transplantation. Discrimination is both an institutional and an individual practitioner matter.

Second, since Penn Medicine's rejection, Corby was also denied a transplant from the Mayo Clinic in Rochester, Minnesota.¹⁴¹ A second rejection does not foreclose the possibility of disability discrimination, but may suggest that there were legitimate considerations in determining his eligibility for transplantation.¹⁴² The Mayo Clinic determined that a transplant was not in Corby's best interest after spending an entire week evaluating him, but for different reasons than Penn Medicine. The Mayo Clinic's denial stated that his survival "with medical therapy over the next five years would likely be comparable to that after cardiac transplantation" based on the Seattle Heart Failure Model and that transplantation would "add not only the stresses of long-term medical followup but would add the risks of complications such as infection, rejection, malignancy, etc."¹⁴³ Essentially, the Mayo Clinic's argument is that his condition currently is too stable to risk the unknowns of transplantation. However, the clinic still noted that it was "concern[ed] about his ability to manage the inevitabl[e] stresses and untoward events that transplant patients have to deal with," insinuating that his autism factored into the denial decision.¹⁴⁴ When Corby's mother asked the clinic what would happen when Corby was no longer stable, according to Ms. Corby, the doctors indicated that they were concerned how he would react while in crisis and forced to meet numerous new people, notwithstanding that they had just observed him in stressful testing situations, meeting new people, without any outbursts or objections.¹⁴⁵ These final facts bring the Mayo Clinic's denial into question. Although it went further than Penn Medicine in evaluating Corby and cited objective medical criteria in its reasoning for denying him access

141. Leskin, *supra* note 123.

142. See *supra* Part III.E (discussing disability as a legitimate consideration in medical decisions).

143. Letter from Mayo Clinic to Karen Corby (Oct. 15, 2012) (on file with author).

144. *Id.*

145. Email from Karen Corby to Danielle Richards (Nov. 21, 2012, 4:07 AM) (on file with author). The Mayo Clinic's reasoning here is twofold: first, Corby is currently too stable to necessitate transplantation; second, when his condition deteriorates to the point where he would need a transplant, the center is reluctant to place him on the heart waitlist because of possible compliance and behavioral issues that may occur years from now. The willingness of the center to make such a broad assumption about Corby's ability to comply ten years from now may suggest that social worth factors are actually at play here.

to the heart transplant waitlist, the clinic's reluctance to reevaluate him at a later date implies that its denial may be pretext for discrimination.

Ultimately, the structure of the current transplantation process—namely, that physicians are given broad medical discretion in determining patient eligibility for placement on the national transplantation waitlists—and the subjectivity of the initial evaluation criteria as a whole, make it difficult to say whether Corby's rejections were discriminatory or legitimate considerations.

B. AMELIA RIVERA: WOLF-HIRSCHHORN SYNDROME AND THE INITIAL DENIAL OF ACCESS TO THE KIDNEY TRANSPLANT WAITLIST

Unlike Corby's transplant denial, some instances of unfair treatment are more clear-cut. Take, for example, three-year-old Amelia Rivera who is in kidney failure as a result of Wolf-Hirschhorn Syndrome, a genetic disorder that has left her developmentally delayed and unable to walk or talk. In January 2012, Rivera's kidneys were functioning at about 15 percent of normal and her doctors at the Children's Hospital of Philadelphia told her parents that she would need a kidney transplant when her kidney functioning reached approximately 10 percent.¹⁴⁶ The doctors' next moves, however, shocked Rivera's parents and the public at large. According to the Riveras, the doctors explained that they would not place her on the national kidney waitlist because she is "mentally retarded."¹⁴⁷ When her parents stated they would pursue direct donation from a matching family member as an alternative, the doctors clarified their position: they would not perform a kidney transplant on her regardless of a direct donor because, in their opinion, her quality of life postsurgery would be limited.¹⁴⁸ The hospital's social worker also reminded Rivera's parents that kidney transplants are only effective for about twelve years, in which case she would need multiple transplants throughout her life to survive, not to mention daily medications that might interfere with Rivera's current medications.¹⁴⁹ The social worker then asked what would happen when Rivera was an adult and her parents were no longer able to care for her,

146. Lisa Belkin, *Amelia Rivera, Girl Who Sparked Debate over Transplants and "Mental Retardation," to Receive New Kidney from Mom*, HUFFINGTON POST (Aug. 8, 2012, 8:24 AM), http://www.huffingtonpost.com/2012/08/07/amelia-rivera-kidney-transplant_n_1753851.html.

147. Chrissy Rivera, *Brick Walls*, WOLFHIRSCHHORN.ORG (Jan. 12, 2012), <http://wolhirschhorn.org/2012/01/amelia/brick-walls/>.

148. *Id.*

149. Rivera, *supra* note 147. Ryan Jaslow, *Mom Says Disabled Daughter Denied Lifesaving Kidney Transplant*, CBS NEWS (Jan. 17, 2012), <http://www.checkorphan.org/grid/news/people/mom-says-special-needs-daughter-denied-life-saving-kidney-transplant>.

regardless of the fact that this situation likely would occur many years from now—far past the twelve-year life of a transplant. If a transplant does allow a recipient to live into old age, that person, too, will likely need additional support that would be similar to that provided to Rivera by her family for the foreseeable future. Thus, while we should promote nonfutile transplants to avoid wastage, arguments regarding long-term support and outcomes can be subterfuge for social worth bias against individuals with mental disabilities. Moreover, the social worker's comment ignores the fact that we not only value utility, but also fairness.

Rivera's parents, like Karen Corby, started an online petition to publicize their daughter's denial. Unlike Corby's situation, however, the hospital quickly recanted, approving her for the waitlist after "[a]ll of her specialists . . . agreed that there is no medical reason for her not to have the transplant," and publicly apologized to her parents.¹⁵⁰ The hospital also agreed to review its policies regarding transplantation denials based on mental disability,¹⁵¹ stating that "[w]hile we can unequivocally state that we do not disqualify transplant patients on the basis of intellectual ability . . . this event underscores the importance of our responsibility to effectively communicate with families."¹⁵² After undergoing match testing, Rivera's mother will donate a kidney to her daughter, once her "kidney function falls to about ten percent."¹⁵³

Rivera's situation and the hospital's quick recant show how easily disability can affect an individual's eligibility to receive a transplant, whether or not the disability is medically contraindicated for transplant. Additionally, her doctor's reasoning that her quality of life was a legitimate reason to deny her a transplant is also troubling, since determining one's quality of life is, at best, murky and highly subjective, and at worst, a cover for social worth and moral evaluation of a life.¹⁵⁴

150. Kim Painter, *Philadelphia Hospital Apologizes to Family of Amelia Rivera*, USA TODAY (Feb. 15, 2012 6:38 PM), <http://yourlife.usatoday.com/health/healthperspective/post/2012-02-15/philadelphia-hospital-apologizes-to-parents-of-disabled-girl-amelia-rivera-over-handling-of-transplant-decision/628746/1>; Chrissy Rivera, *Kidney Chronicles Part Three*, WOLFHIRSCHHORN.ORG (Aug. 6, 2012), http://wolhirschhorn.org/2012/08/amelia/kidney-chronicles-part-three/?utm_source=twitterfeed&utm_medium=facebook.

151. Painter, *supra* note 150.

152. Press Release, Joint Statement of the Rivera Family and the Children's Hospital of Philadelphia (Feb. 15, 2012), *available at* <http://wolhirschhorn.org/2012/02/amelia/joint-statement-of-the-rivera-family-and-the-children%E2%80%99s-hospital-of-philadelphia/>.

153. Rivera, *supra* note 150.

154. In extreme cases such as anencephaly or the lack of higher-order brain stem functioning, a quality of life decision may be more justified if it would not yield postoperative success. Notwithstanding, these determinations still should require individual evaluation of the patient.

C. SANDRA JENSEN: DOWN SYNDROME AND THE INITIAL DENIAL OF
ACCESS TO THE HEART-LUNG TRANSPLANT WAITLIST

Corby's and Rivera's dilemmas are not new or especially unique in the world of transplantation.¹⁵⁵ In 1995, thirty-five-year-old Sandra Jensen, an individual with Down Syndrome, was denied placement on the national heart-lung waitlist by transplant centers at Stanford and the University of California, San Diego.¹⁵⁶ Jensen had a congenital heart defect commonly found in individuals with Down Syndrome; the interrelationship of the lungs and heart resulted in her lungs also being affected.¹⁵⁷ These centers initially rejected Jensen for a heart-lung transplant solely on the theory that individuals with Down Syndrome are inappropriate candidates for transplantation because of its possible effect on their ability "to navigate through possible complications that could occur after the transplantation," understand and comply with postsurgical treatment, and care for themselves.¹⁵⁸ What the doctors did not know or take time to discover was that Jensen was highly independent: she had lived alone since she was twenty years old,¹⁵⁹ worked as a consultant with a disability rights nonprofit organization, was a conference speaker, and attended the signing of the ADA as a guest of the president.¹⁶⁰ After public outcry and warnings that her denial may constitute a violation of the ADA, the centers reevaluated her candidacy and she was placed on the transplant waitlist. In January 1996, Jensen became the first individual with Down Syndrome to receive a heart-lung transplant.¹⁶¹ She died sixteen months after her transplant, not from noncompliance, but from lymphoma, which is a common side effect of antirejection immunosuppressants.¹⁶² In fact, her cardiologist, "commend[ed] Jensen on the diligence with which she followed her complicated medical regimen, 'never once [having] one

155. See also Joseph Shapiro, *Disabled Woman Dies While Awaiting Second Chance at Kidney Transplant*, NAT'L PUB. RADIO (June 13, 2012, 11:13 AM), <http://www.npr.org/blogs/health/2012/06/13/154914089/disabled-woman-dies-while-awaiting-second-chance-at-kidney-transplant> (recounting the experience of Misty Cargill, a woman with a "mild intellectual disability" in need of a transplant).

156. Mary Crossley, *Becoming Visible: The ADA's Impact on Health Care for Persons with Disabilities*, 52 ALA. L. REV. 51, 65 (2000).

157. Jennifer L. Gibson, *Who Will Receive the Organs: Will You Receive A Lifesaving Transplant If You Have A Disability?*, 28 PAC. L.J. 916, 916 (1997).

158. Angela T. Whitehead, *Rejecting Organs: The Organ Allocation Process and the Americans with Disabilities Act*, 24 AM. J.L. & MED. 481, 481 (1998). See also Gibson, *supra* note 157, at 919.

159. Whitehead, *supra* note 158, at 481.

160. Gibson, *supra* note 157, at 916.

161. *Id.*

162. Whitehead, *supra* note 158, at 497 & n.170.

problem with not taking her medications or managing her care.”¹⁶³

Jensen’s case illustrates the importance of individual evaluation of transplant candidates to determine their postoperative compliance abilities. Her automatic, categorical rejection was a clear display of how using mental disability as a contraindication to transplantation before individual evaluation of the patient can unfairly deny an eligible individual with mental disability access to lifesaving treatment. Whereas the physicians in Rivera’s case seemed to make quality of life decisions regarding individuals with mental disabilities, Jensen’s physicians at Stanford made arguments based on wastage, noting that “[w]e don’t want to do something that doesn’t have really an optimum chance of survival,” because “[t]here are a lot of people that are waiting, and also we’re under a lot of scrutiny for the results of our program.”¹⁶⁴ Although these arguments may overlap—some argue that long-term survival at a low quality of life is wastage—wastage in its purest sense does not consider quality of life results, only physical success of transplantation. Nevertheless, both arguments require stringent review when used to deny patients with mental disabilities transplantation because they can easily be pretext for discrimination. As the studies discussed in Part II.A.2 indicate, recent evidence that candidates such as Jensen do have an optimum chance at survival—in her case living entirely on her own and, in other cases, with appropriate familial and other assistance—make decisions based on automatic psychosocial contraindications likely pretext for social worth bias.

V. LEGISLATIVE AND REGULATORY BACKLASH TO ALLEGATIONS OF DISCRIMINATION

Although instances such as those above happen regularly, neither the federal government nor any state has enacted legislation prescribing

163. *Id.* (quoting Jensen’s physician, Dr. Bach).

164. Carey Goldberg, *Case: Sandra Jensen (abstracted from N.Y. Times)*, STANFORD UNIV. (March 3, 1996), <http://www.stanford.edu/~mvr2j/sfsu09/extra/SandraJensen.pdf>. Here, the physicians were not clear as to what constitutes an “optimum chance of survival”; however, in my conversation with a local transplantation surgeon, it was explained to me that the federal government monitors survival rates for three years after surgery; thus, this is likely the minimum survival time that physicians would look to achieve. If the surgical center’s survival rates fall below a certain threshold, it will affect the center’s Medicaid and Medicare reimbursements, which means that centers not only have an incentive to ensure a patient’s compliance ability from a scarcity perspective, but also for personal financial reasons. Hence, it becomes more likely, in theory, that these incentives will result in higher surgical success rates, but it may be at the cost of marginal patients. This makes it even more imperative that physicians consciously avoid making uninformed assumptions about a particular person’s ability to comply in their evaluation of that individual.

acceptable evaluation criteria and weighting for determining whether an individual should be placed on an organ transplantation waitlist. Moreover, while states and the federal government have laws protecting individuals with disabilities, only one state—California—has a specific provision ensuring such individuals' right to be considered eligible for transplantation and specifying compliance accommodations. In July 2013, New Jersey joined the ranks with California, enacting its own antidiscrimination statute in the context of transplantation. The legislative reemergence of this issue indicates changing attitudes toward individuals with disabilities and slow recognition that, without uniform federal guidelines regarding appropriate eligibility criteria, the states must take responsibility to protect their citizens.

A. CALIFORNIA'S RESPONSE TO SANDRA JENSEN'S CASE

Jensen's experience resulted in the California legislature passing an antidisability discrimination law for transplantation.¹⁶⁵ California Health and Safety Code section 7151.35 prohibits discrimination with respect to referrals to specialists, referrals from specialists to transplant centers, initial evaluations of patients for waitlist eligibility, and placement on the waitlist.¹⁶⁶ It also requires that, for each stage in the transplantation process

[n]o hospital, physician and surgeon, procurement organization, or other person shall determine the ultimate recipient of an anatomical gift based upon a potential recipient's physical or mental disability, except 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. . . . *A person with a physical or mental disability shall not be required to demonstrate postoperative independent living abilities in order to have access to a transplant if there is evidence that the person will have sufficient, compensatory support and assistance.*¹⁶⁷

In a system that has no explicit federal protections for individuals with disabilities in the transplantation process, California Health and Safety Code section 7151.35 stands out as their only clear protection. In California, individuals with disabilities also have additional protections during the initial evaluation stage, specifying that each case must be looked at individually and that evidence of the likelihood of postoperative

165. HEATHER S. HARRISON, BILL ANALYSIS OF AB 2861, FN 024417, CAL. ASSEMBLY 1-2 (1996), *available at* http://leginfo.ca.gov/pub/95-96/bill/asm/ab_2851-2900/ab_2861_cfa_960510_181831_asm_floor.html.

166. CAL. HEALTH & SAFETY CODE § 7151.35(b) (West Supp. 2013).

167. *Id.* § 7151.35(a), (c) (emphasis added).

compliance can be supported by familial assistance. It is difficult to determine, however, how successful the law has been in actually preventing discrimination because there is no case law on the statute. It is, at least, a step in the right direction.

B. NEW JERSEY'S RESPONSE TO AMELIA RIVERA'S EXPERIENCE

Rivera's story also has sparked change in her home state of New Jersey. In July 2013, New Jersey enacted sections 26:6-86.1–2 to its state code, which parallels the California law:

An individual who is a candidate to receive an anatomical gift shall not be deemed ineligible to receive an anatomical gift solely because of the individual's physical or mental disability, except to the extent that the physical or mental disability has been found by a physician or surgeon, following *an individualized evaluation of the potential recipient*, to be medically significant to the provision of the anatomical gift. *If an individual has the necessary support system to assist the individual in complying with post-transplant medical requirements, an individual's inability to independently comply with those requirements shall not be deemed to be medically significant.* The provisions of this subsection shall apply to each part of the organ transplant process.¹⁶⁸

The New Jersey law is slightly different from its California counterpart: California prohibits consideration of disability except when found to be medically significant after an individual evaluation of the patient. New Jersey's law prohibits using disability as the *sole* factor for rejection, except when medically significant after individual evaluation. This exception seems more lenient than the California law.

Ultimately, the California and New Jersey laws are both weak in some respects and strong in others. For example, the exception that mental disability can be taken into account after an individualized evaluation, seems to only require that some rational reason be given for the denial and does not appear to require much scrutiny by the courts. Nevertheless, this is no different from what the ADA requires, provided that the evaluation criteria are not subterfuge for discrimination. On the other hand, the requirement that independence, or the lack thereof, cannot be taken into account if the individual has a support system in place gives teeth to the ADA's reasonable accommodation requirement by providing at least one example of modifications that centers must accept to determine eligibility. These requirements, however, do not go as far as Orentlicher's assertions that the centers may be affirmatively required to provide such additional

168. N.J. STAT. ANN. §§ 26:6-86.2 (West 2013) (emphasis added).

support;¹⁶⁹ they only specify that if support is present, independence cannot be a factor in determining the likelihood of noncompliance.

C. POSSIBLE ELIGIBILITY GUIDANCE FROM HEALTH AND HUMAN SERVICES

Corby's and Rivera's experiences have reinforced interest in the ethical and legal considerations of transplantation eligibility and allocation policies. In response, representatives from the National Disability Leadership Alliance, a fourteen-member coalition of disability advocacy groups, met with senior staff from HHS's Division of Transplantation in September 2012, asking the HHS Secretary to provide "strong and unequivocal legal guidance" to physicians and transplant centers regarding the ADA to raise awareness of their respective obligations.¹⁷⁰ Ari Ne'eman, president of the Autistic Self Advocacy Network, which is a member of the National Disability Leadership Alliance, commented that HHS seemed open to this request.¹⁷¹ However, issuing formal guidance, if any, entails a long and detailed process. With this in mind, it is important for policymakers, ethicists, and lawyers to consider (1) how physicians' and transplant centers' evaluation policies for placing individuals on the waitlists comply with the ADA, and (2) how theories of distributive justice would comport with HHS's Final Rule and the OPTN's national policies.

VI. PROPOSAL FOR FEDERAL REGULATION AND PHYSICIAN GUIDELINES

In light of the above, it seems clear that legislative or regulatory action is needed in the initial evaluation stage for transplant waitlist eligibility to safeguard individuals with mental disabilities from possible bias and unfair treatment resulting from the use of psychosocial criteria as proxies for social worth. To achieve this, a variety of solutions may individually or jointly serve to protect individuals with mental disabilities from unfair treatment:

- (1) amending NOTA to explicitly cover the initial evaluation stage of the transplantation process,

169. See *supra* Part III.E.2 (discussing ADA reasonable accommodations for transplantation).

170. Joslyn Gray, *Disability Advocacy Groups Push for 'Strong, Unequivocal' Legal Guidance on Organ Transplants*, BABBLE (Sept. 26, 2012, 3:25 PM), <http://blogs.babble.com/strollerderby/2012/09/26/disability-advocacy-groups-push-for-strong-unequivocal-legal-guidance-on-organ-transplants/>. See also Michelle Diament, *Advocates Call for End to Transplant Discrimination*, DISABILITY SCOOP (Sept. 21, 2012), <http://www.disabilityscoop.com/2012/09/21/advocates-end-transplant/16494/>.

171. Diament, *supra* note 170.

- (2) adopting language similar to California Health and Safety Code section 7151.35 within NOTA or the ADA,
- (3) providing regulatory guidance to transplant centers on the application of the ADA to the transplantation process,
- (4) regulating that the OPTN create policies regulating the criteria that hospitals and transplant centers should use to determine waitlist eligibility, including when psychosocial factors can be considered and how outside support should factor into compliance determinations, and
- (5) litigating, if possible in California, cases in which individuals with mental disabilities are denied access to a transplant waitlist.

The most reasonable and probably effective of these solutions would be a combination of HHS guidelines to transplant centers and regulations to the OPTN to create policies for initial waitlist eligibility criteria similar to its policies for the allocation stage. However, pursuing any of these options would be a step forward for creating uniform and objectively measurable waitlist eligibility criteria.

A. CONGRESSIONAL AMENDMENT OF THE NATIONAL ORGAN TRANSPLANTATION ACT OR THE AMERICANS WITH DISABILITIES ACT

Although a congressional amendment to NOTA or the ADA would provide the strongest teeth for prohibiting discrimination against individuals with disabilities, it also likely would be the most difficult to accomplish. The American Medical Association and other hospital and physician lobbies hold great power in national politics and may oppose any legislation that appears to remove the discretionary power of a hospital's or physician's independent medical judgment. To some extent, hospital and physician discretion is not only permissible, but also advisable; however, not at the expense of denying individuals with mental disabilities access to lifesaving treatment. After all, placement on the waitlist does not guarantee an individual that he will receive an organ; it only makes the individual eligible to receive one.

Additionally, if language similar to California Health and Safety Code section 7151.35 was incorporated into NOTA, it could help to provide clear, but general guidelines to physicians and transplant centers, while still allowing them broad medical discretion except in the application of psychosocial criteria for determining compliance if the patient can demonstrate independence or sufficient support systems. If the amendment were incorporated into the ADA, however, it could likely go farther, explaining what, if any, reasonable accommodations to the transplantation process would be affirmatively required of private or public transplantation

centers.

B. HHS GUIDANCE OR REGULATIONS TO THE OPTN

The most probable and expeditious solutions would be for HHS to implement regulations requiring UNOS, as the OPTN administrator, to create initial waitlist evaluation criteria policies specifying the appropriate use of psychosocial criteria. Specifically, HHS guidelines to transplant centers should explain social worth bias and the requirements of the ADA, and should suggest how to use psychosocial criteria properly in the initial evaluation stage to avoid social worth determinations and ADA violations when evaluating individuals with mental disabilities. Like the California law, these guidelines should explicitly state that threshold evidence of a support system shall be treated as the equivalent of independence for determining the risk of an individual's noncompliance. If HHS promulgates rules requiring UNOS to create initial evaluation criteria, it should also specify that UNOS is responsible for reviewing claims of unfair treatment or discrimination during the evaluation stage and provide a mechanism for redress similar to what is available for the allocation stage. To avoid allegations that disability discrimination allegations are given greater redress options than other forms of discrimination, it is advisable that the review board should be opened to all allegations of statutorily prohibited discrimination. Although this could cause the OPTN to incur additional expense administering and reviewing grievances, since there have been few to no examples of state or federal cases regarding mental disability discrimination in the transplantation process, it is unlikely that such a process would drastically disrupt UNOS. Nevertheless, it would provide an additional avenue of redress for those individuals who feel truly wronged.¹⁷²

If HHS does not provide regulatory oversight and clarification, however, it is still advisable for transplant centers and national transplantation medical societies to provide guidance to their physicians and members. There are some guidelines by national transplantation societies, such as the International Society for Heart and Lung Transplantation's¹⁷³ and the Patient Care and Education Committee of the

172. Other categories of discrimination, however, may create more grievance procedures for the OPTN. See generally RM Sade, *Transplantation, the Organ Gap, and Race*, 95 J. S.C. MED. ASS'N 112, available at <http://academicdepartments.musc.edu/humanvalues/pdf/Transplantation-the-organ-gap-and-race.pdf> (discussing the issue of race disparity in the organ allocation process).

173. Mehra, *supra* note 50, at 1034. These guidelines, however, are not ideal as they presuppose that mental disability is a relative contraindication to transplantation. Also, the guidelines regarding social worth are vague, stating that psychosocial factors "predictive of outcome are not confused with

American Society of Transplant Physicians' guidelines for basic eligibility considerations.¹⁷⁴ However, these guidelines currently only state that social worth should not be considered during eligibility evaluations. These guidelines should go beyond general statements and should explain how such determinations enter into the decisionmaking process and how to avoid them.

C. JUDICIAL ACTION BY ALLEGEDLY WRONGED INDIVIDUALS WITH MENTAL DISABILITIES

The final option for reforming the initial evaluation stage of the current transplantation system is to have judicial review of evaluation criteria to determine their legality under NOTA, the ADA, or state laws. This option, however, would be slow and would likely create piecemeal and inconsistent decisions. Therefore, it may provide relief to specific individuals, but without Supreme Court review, it would not create uniformity for transplantation centers throughout the United States.

VII. CONCLUSION

In creating a system for allocating scarce resources, such as organs for transplantation, society is forced to make difficult decisions about distributive justice. Should the criteria be based on equality, fairness, justice, autonomy, or utility? Within these standards, which forms of equality, utility, and so forth are we to apply? Which criteria will maximize our preferred forms of these basic values? Ultimately, any criteria used to determine individual candidacy or allocation rankings for transplantation will favor, whether deliberately or incidentally, one group of individuals over another. For this reason, when discussing or establishing eligibility or allocation criteria for transplantation, one must do so with eyes wide open to the fact that a decision to place another person on the transplant waitlist and subsequently allocate an organ to a specific individual necessarily saves one individual with certain qualities at the expense of another. Thus, the evaluation criteria and allocation policies we choose are vitally important and we should strive to not only create a system that works to eliminate invidious discrimination against individuals with mental disabilities who are otherwise qualified to receive transplantation, but also

judgments of an individual's social worth," but does not explain what social worth means.

174. Martens, Jones & Reiss, *supra* note 31, at 660 (stating that the Patient Care and Education Committee of The American Society of Transplant Physicians has guidelines for kidney transplantation, specifying that mental disabilities "should only be considered a contraindication to transplantation when the cognitive impairment is so severe that it impairs compliance with essential medical regimens").

to eliminate underlying social biases that unfairly disadvantage these individuals in accessing transplant surgeries. States such as California and New Jersey have taken steps in the right direction, but for a lifesaving issue like transplantation, uniform federal guidance is desperately needed. Now is the time to ensure future patients like Corby, Rivera, and Jensen do not face a higher standard for eligibility than is required for patients without mental disabilities.