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ARTICLE

Recalibrating Transplant Eligibility Criteria: Ensuring Equitable Access to Organ Transplantation for Intellectually Disabled Persons

Adam Peña

Baylor College of Medicine, Houston, TX, USA
Email: apena@houstonmethodist.org

Abstract

The American with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act have made little progress towards preventing disability-based discrimination within the organ transplant evaluation process. Intellectual and developmental disabilities (I/DD) pose a unique problem for transplant teams and transplant physicians because I/DDs can simultaneously be a legitimate contraindication for transplantation and a mechanism for invidious discrimination against intellectually disabled persons. A culprit for ongoing disability-based discrimination is a transplant center's authority to develop its own eligibility criteria. While medical criteria for eligibility are generally well-settled, psychosocial criteria — an amorphous constellation of risk factors for post-transplant success — can serve as a facially neutral disguise for social worth determinations of individuals with I/DDs. Consequently, individuals with I/DDs are unjustifiably denied eligibility for organ transplantation and transplant-related services.

This Article begins by identifying the pitfalls of current federal antidiscrimination legislation. It then discusses the foreseen benefits and drawbacks of House Resolution (H.R.) 8981, a recently proposed federal bill, that expressly prohibits disability-based discrimination within the organ transplant evaluation process. The Article ends by offering potential solutions for professional organizations and transplant centers that aim to provide for equitable access to organ transplantation and transplant-related services for intellectually disabled individuals.

Keywords: solid organ transplantation; disabilities; Americans with Disabilities Act; disability-based discrimination; intellectual and development disabilities

Introduction

Each week, an interdisciplinary medical review board (MRB) evaluates and determines an individual's eligibility for solid organ transplantation. Solid organ transplantation is a surgical operation that treats end-stage organ dysfunction of kidneys, liver, heart, intestines, lung, and pancreas.[1] Ultimately, the MRB will decide whether an individual is a suitable candidate for solid organ transplantation; as part of the decision-making process, members of the MRB consider various medical and psychosocial factors that weigh in favor of or against the individual's candidacy for solid organ transplantation.

The MRB's decision is an exercise in the allocation of an extraordinarily scarce medical resource: a viable human organ. The United Network for Organ Sharing (UNOS), a non-profit organization that manages the United States organ transplant system under contract with the federal government,[2] reports

[1]Cara K. Black et al., *Solid Organ Transplantation in the 21st Century*, 6 Annals of Translational Med. 409, 409 (2018).
[2]*About UNOS: Saving Lives Together*, UNOS, https://unos.org/about/UNOS [https://perma.cc/JTT9-XU6U] (last visited Aug. 8, 2021).

that 107,375 individuals are currently listed for an organ transplant.[3] Despite targeted initiatives to increase organ donors, the number of viable organs falls well below the increasing number of listed transplant candidates.[4] One culprit for an insufficient organ supply is the shortcomings of this country's sole reliance upon an altruistic allocation system of organ donation.[5] Absent the willingness of the general public to support organ donation, the demand will continue to outpace the supply. Increased demand for organs on an already limited (and dwindling) supply creates pressure on transplant centers and its physicians to ensure successful post-transplant clinical outcomes. It is against this backdrop that transplant eligibility decisions can appear biased against marginalized populations (e.g., ethnic and racial minorities).[6]

Given the continued scarcity of available organs, MRBs must prioritize some individuals for organ transplant candidacy over others based on the individual's medical and psychosocial compatibility to receive an organ. The consequence of these high-stakes decisions is that inevitably, some individuals are denied access to a life-sustaining and life-saving medical intervention. The MRB's everyday function and scope of authority underscores the vital importance of an organ transplantation system that promotes the equitable access to the organ transplantation system for intellectually disabled individuals. Despite a renewed national recognition of the value and inclusion of persons with intellectual and developmental disabilities (I/DDs) among organ recipients, several high-profile media news cases provide anecdotal evidence that transplant centers are continuing to deny individuals with I/DDs, who are otherwise eligible for organ transplantation, based on the individual's I/DD.[7] Consider the case of three-year-old Amelia Rivera, who was developmentally delayed as a result of Wolf-Hirschhorn Syndrome, a genetic disorder.[8] Transplant physicians deemed Amelia categorically ineligible for organ transplantation because they believed that an organ transplant would not provide sufficient medical benefit to improve her already limited quality of life.[9]

The Diagnostic and Statistical Manual of Mental Disorders characterizes I/DDs as "developmental conditions characterized by significant deficits in both intellectual functioning and adaptive behavior, including conceptual, social, and practical skills."[10] The American Association of Intellectual and Developmental Disabilities has published a similar definition.[11] Transplant teams' or transplant physicians' denials of transplant eligibility for intellectually disabled individuals warrants examination, because an I/DD can simultaneously serve as a legitimate medical contraindication for organ transplant and a vehicle for disability-based discrimination.[12] The utilization of an I/DD as a contraindication for transplant remains unsettled.[13] Empirical evidence demonstrates that of 122 cardiac transplant

[3]*National Data*, OPTN, https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/# [https://perma.cc/S83M-WSAW] (last updated June 5, 2021).

[4]*See The Success of National Organ Donation and Transplant System*, UNOS, https://unos.org/about/success-of-national-organ-donation-and-transplant-system/ [https://perma.cc/3J6S-M7H6] (last visited June 6, 2021).

[5]Arthur L. Caplan, If I were A Rich Man Could I Buy a Pancreas? And Other Essays on the Ethics of Healthcare 159 (1992); Michele Goodwin, Black Markets: The Supply and Demand of Body Organs 10 (2006). An altruistic system of organ donation relies upon the public's concern for the disinterested well-being for other individuals who may need an organ transplant.

[6]Goodwin, *supra* note 6, at 15.

[7]Laura C. Hoffman, *Access to Health Care and the Intellectually and Developmentally Disabled: Anti-Discriminatory Law, Health Law, and Quality of Life*, 22 J. Gender, Race & Just. 151, 155 (2019); Danielle Richards, *The Defibrillation of NOTA: How Establishing Federal Regulation Waitlist Eligibility May Save Organ Transplant Patients with Disabilities from Flat-Lining*, 87 S. Cal. L. Rev. 151, 164 (2013).

[8]Richards, *supra* note 8, at 153.

[9]*Id.*

[10]Am. Psychiatric Ass'n, Diagnostic and Statistical Manual of Mental Disorders: DSM-5 33 (5th ed. 2013).

[11]*Defining Criteria for Intellectual Disability*, Am. Ass'n of Intell. & Dev. Disabilities, https://www.aaidd.org/intellectual-disability/definition [https://perma.cc/WDE9-HFC7] (last visited Oct.12, 2022).

[12]Richards, *supra* note 8, at 156.

[13]Ashton Chen et al., *Access to Transplantation for Persons with Intellectual Disability: Strategies for Nondiscrimination*, 20 Am. J. Transplant 2009, 2010 (2020); Nat'l Council on Disability, Organ Transplant Discrimination Against

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programs, 217 renal transplant programs, and 72 liver transplant programs, more than 50% of programs regard intellectual disability as a contraindication to transplant.[14] This suggests that the medical community may espouse an implicit assumption that the presence of an I/DD, regardless of the degree of severity, jeopardizes post-transplant success. This assumption is ethically and legally problematic when the I/DD does not significantly diminish the medical benefits of an organ transplant for the individual and the individual is otherwise medically compatible to receive an organ. This is likely not altogether surprising given the distinct possibility that oftentimes, physicians' attitudes about disability "trail behind the law."[15]

Federal antidiscrimination statutes like the American with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act prohibit disability-based discrimination by state-run hospitals. Federal antidiscrimination prohibitions are applicable to hospitals that receive federal funding, including privately-run hospitals. Several states have enacted legislation that prohibit transplant centers within the state from denying eligibility for organ transplantation on the basis of I/DDs and other physical disabilities.[16] But current federal statutory and regulatory protections remain less effective at preventing discrimination within the organ transplantation arena than originally anticipated.[17] Further, the National Organ Transplant Act (NOTA) and relevant federal regulations govern the allocation of organs once an individual is listed for organ transplant.[18] Therefore, the assessment of organ transplant eligibility and the selection of transplant candidates fall outside the scope of existing federal statutes and regulations. Absent federal guidance providing appropriate selection criteria for organ transplantation, transplant teams at transplant centers retain wide latitude to determine their own eligibility criteria and considerable discretion in the application of the criteria when assessing an intellectually disabled individual's eligibility for organ transplant.[19] As a result, (1) transplant centers' eligibility criteria include I/DD as a relative or absolute contraindication for organ transplantation and (2) disability-based denials for organ transplant eligibility of a qualified individual are masked by facially neutral eligibility criteria.[20]

House Resolution (HR) 8981 is a recently submitted antidiscrimination bill that, if enacted, would "prohibit discrimination on the basis of mental or physical disability in cases of anatomical gifts and organ transplants."[21] The bill supplements other federal antidiscrimination statutes and efforts to remedy the inadequacies (e.g., ambiguity) of existing federal legislation.[22] Whereas current legislation affords sweeping protections, the bill's more tailored scope proposes a solution to the discriminatory barriers that bar entry to the organ transplant system for individuals with I/DDs.

People with Disabilities: Part of the Bioethics & Disability Series, 12-1313 (2019), https://ncd.gov/sites/default/files/NCD_Organ_Transplant_508.pdf [https://perma.cc/6MF7-M6ZM].

[14]Chen et al., *supra* note 14, at 2010.

[15]Elizabeth F. Emens, *Framing Disability*, 2012 Univ. Ill. L. Rev 1383, 1385 (2012). The American Association of Intellectual and Developmental Disabilities provides the following definition for an intellectual disability: a condition characterized by significant limitations in both intellectual functioning and adaptive behavior that originates before the age of 22.

[16]Hoffman, *supra* note 8, at 152; Nat'l Council on Disability, *supra* note 14, at 57; Tien-Kha Tran, *Organ Transplantation Eligibility: Discrimination on the Basis of Cognitive Disability*, 24 J.L. & Pol'y 631, 651-54 (2016); *Lawmakers Introduce Federal Legislation To Prevent Organ Transplant Discrimination*, Nat'l Down Syndrome Soc'y (Dec. 17, 2020), https://www.ndss.org/lawmakers-introduce-federal-legislation-prevent-organ-transplant-discrimination/ [https://perma.cc/EKG7-6NZ5]. California, Delaware, Kansas, Maryland, Massachusetts, New Jersey, Ohio, Oregon, Indiana, Louisiana, Virginia, Iowa, Missouri, and Pennsylvania are the fourteen states who have enacted antidiscrimination laws.

[17]Hoffman, *supra* note 8, at 165; Angela T. Whitehead, *Rejecting Organs: The Organ Allocation Process and the American with Disabilities Act,* 24 Am. J.L. & Med. 489, 491 (1998); *see* Richards, *supra* note 8, at 159.

[18]Richards, *supra* note 8, at 155, 170-71.

[19]Nat'l Council on Disability, *supra* note 14, at 26; Richards, *supra* note 8, at 154; Sara Frank, *Eligibility Discrimination of the Intellectually Disabled in Pediatric Organ Transplantation*, 10 J. Health & Biomedical L. 101, 104 (2014).

[20]Nat'l Council on Disability, *supra* note 14, at 30; Richards, *supra* note 8, at 153; Frank, *supra* note 20, at 106; Chen et al., *supra* note 14, at 2010.

[21]H.R. Res. 8981, 116th Cong. (2020).

[22]Tran, *supra* note 17, at 637.

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This Article begins with an overview of the organ transplant evaluation process. The first part suggests that transplant centers' utilization of I/DDs as a relative or absolute contraindication for eligibility for organ transplantation promotes discriminatory selection practices that deny access to organ transplantation for individuals with I/DDs. Part II argues that refusing to actively list individuals with I/DDs on the basis of disability and accompanying misperceptions of individuals with I/DDs is a discriminatory practice that is violative of the ADA and Section 504 of the Rehabilitation Act. Part II concludes with a discussion of the shortcomings of current federal disability statutes. Part III opens with a description of H.R. 8981 as a proposed legislative solution to offset the pitfalls of the ADA and Rehabilitation Act, then shifts to a discussion of the bill's anticipated benefits and drawbacks. Part IV offers several practical solutions that could serve to address disability-based eligibility decisions during the evaluation process at transplant centers.

Ongoing discrimination against individuals with I/DDs

Viable organs available for transplantation are a scarce medical resource. They are distributed using allocation systems that direct organs to candidates who are anticipated to receive medical benefit from those organs. Allocation (or triage) decisions are value-laden empirical judgments.[23] While the national organ allocation system is heavily regulated, transplant physicians have broad authority to determine candidate suitability. Despite the physician's technical medical expertise, the physician's underlying values and biases related to disability — whether implicit or overt — inevitably influence decisions about an individual's transplant eligibility.[24] This reality is especially concerning when contextualized against the significant body of empirical evidence demonstrating physicians' biases against disability.[25] The suggestion that negative assumptions influence transplant eligibility decisions is likely uncontroversial as these types of assumptions stem, in part, from a medical model, as opposed to a social model, of disability. A medical model of disability characterizes disability as a medical pathology inherent to the individual.[26] As such, the medical model of disability is framework imbued with the values of the medical profession, including a historically societal understanding that clinicians are the "authority on determining abilities, conditions, and 'body knowledge.'"[27] In this backdrop, the distinct possibility emerges that categorical denials of eligibility for intellectually disabled individuals often rest upon unfavorable biases towards I/DDs. In an effort to evaluate this possibility, Section A of Part I describes the organ transplantation evaluation process, and Section B explores the cited reasons for denials of eligibility for intellectually disabled individuals.

Transplant candidacy evaluation

A transplant center's eligibility criteria establish minimum thresholds aimed at ensuring successful transplant outcomes. Anticipated transplant outcomes (e.g., graft survival) are relevant and appropriate considerations for organ transplant evaluations and eligibility determinations.[28] Assuming a physician refers a patient to a transplant center, a multidisciplinary team will evaluate a person's candidacy for solid

[23]Samuel R. Bagenstos, *Who Gets the Ventilator? Disability Discrimination in COVID-19 Medical-Rationing Protocols*, 130 Yale L.J. Forum 1, 8 (2020).

[24]Bagenstos, *supra* note 24, at 8.

[25]Begenstos, *supra* note 24, at 4; Alice Bacherini et al., *Physcians' Attitudes About Individuals with Intellectual Disability and Health Care Practices Towards Them: A Systematic Review*, 33 Psychiatria Danubina 79, 87 (2021); Lisa I. Iezzoni et al., *Physicians' Perceptions of People with Disability and Their Health Care*, 40 Health Affs. 297, 303 (2021).

[26]Emens, *supra* note 16, at 1401.

[27]Doron Dorfman, *Re-Claiming Disability: Identity, Procedural Justice, and the Disability Determination Process*, 42 L. & Soc. Inquiry 195, 199.

[28]Hoffman, *supra* note 8, at 170; Mindy Statter et al., *Children with Intellectual and Developmental Disabilities as Organ Transplantation Recipients*, 145 Pediatrics 3 (2020).

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organ transplantation based on the transplant center's own organ transplant eligibility criteria.[29] The evaluation normally consists of two major components: (1) a medical evaluation of the patient's health status and (2) a psychosocial assessment. National medical eligibility criteria for each organ are relatively well-established.[30] Evidence-based guidelines developed by noted experts in the field specific to the organ—like the heart transplant criteria developed by the International Society for Heart and Lung Transplantation—provide further detailed guidance for each organ system.[31]

Psychosocial transplant eligibility criteria is less standardized.[32] The Organ Procurement Transplantation Network (OPTN), a national organ procurement, transplant and donation system, provides general guidance about psychosocial criteria for organ transplantation.[33] The OPTN recommends that transplant centers develop evidence- and policy-based criteria for the psychosocial component of an individual's evaluation for solid organ transplantation.[34] Given the relative absence of evidence-based guidelines for pre-transplant psychological screening, this recommendation remains unheeded.[35] The goal of the psychosocial evaluation is to identify patient-specific risk variables that predict the likelihood of post-transplant success or failure.[36] That is, a standardized evaluation tool is intended to provide an accurate risk severity score that reflects an evidence-based correlation between psychosocial risk factors and clinical transplant outcomes specific to the potential candidate.[37] Generally, a psychosocial evaluation tool categorizes risk variables associated with poor clinical transplant outcomes into different domains. For example, the Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT), an objective psychosocial assessment tool, evaluates a patient's (1) readiness (for transplant), (2) social support, (3) psychological stability and (4) (history of) substance abuse.[38] These types of objective tools provide an overall severity risk score for psychosocial variables that predict post-transplant clinical outcomes and nonadherence.[39] But the paucity of available data regarding psychosocial evaluations suggests that psychosocial evaluation tools may not accurately predict post-transplantation clinical outcomes on the basis of pre-transplant psychosocial risk variables.[40]

The inability to predict post-transplant outcomes consistently is of significance for individuals with I/DDs when it remains less clear if these tools contemplate differences in the psychosocial milieu of (intellectually) disabled individuals. Despite the standardized and objective nature of risk stratification tools that identify psychosocial factors necessary to maximize post-transplant outcomes, the scope and substantive criteria of a psychosocial evaluation remains inconsistent among transplant centers.[41] This author does not intend to ignore the advantages of standardized and predictive evaluation tools that guide clinical decision-making. Rather, this author argues that the variance in scope and content of the evaluative domains of risk stratification tools disproportionately impacts the intellectually disabled patient population seeking transplant evaluations.[42] For example, an objective of the psychosocial

[29]Nat'l Council on Disability, *supra* note 13, at 25; Richards, *supra* note 8, at 154; Hoffman, *supra* note 8, at 169 (quoting *Frequently Asked Questions*, United Network For Organ Sharing, https://unos.org/transplant/frequently-asked-questions/ (last visited Jun. 16, 2021).

[30]Nat'l Council on Disability, *supra* note 14, at 26; Frank, *supra* note 20, at 104-05.

[31]Nat'l Council on Disability, *supra* note 14, at 26.

[32]José R. Maldonado et al., *The Stanford Integrated Psychosocial Assessment for Transplantation: A Prospective Study of Medical and Psychosocial Outcomes*, 77 Psychosomatic Med. 1018, 1018 (2015); *see also* Quan M. Bui et al., *Psychosocial Evaluation of Candidates for Heart Transplant and Ventricular Assist Devices*, 12 Circulation: Heart Failure 2 (2019).

[33]Statter et al., *supra* note 29, at 5; Maldonado et al., *supra* note 33.

[34]Maldonado et al., *supra* note 33, at 124-25.

[35]*Id.* at 125.

[36]Statter et al., supra note 29, at 5; Mary Ellen Olbrisch & James L. Levenson, *Psychosocial Assessment of Organ Transplant Candidates*, 36 Psychosomatics 236, 236 (1995).

[37]Maldonado et al., *supra* note 33, at 126.

[38]*Id.*

[39]*Id.*

[40]*See* Bui et al., *supra* note 33, at 2.

[41]Maldonado et al. 2, *supra* note 33, at 1019.

[42]*See, e.g.,* Frank, *supra* note 20, at 108-09.

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evaluation is to evaluate the potential candidate's intellectual and cognitive functioning.[43] One evaluative domain of the SIPAT is "PATIENT'S READINESS LEVEL and ILLNESS MANGEMENT." Under this domain, a psychosocial evaluator would assess the potential candidate's ability to demonstrate a knowledge and understanding of both her medical illness and the transplantation process.[44] Absent modifications that account for differences in intellectual and cognitive functioning (or modifications to a transplant center's practices and procedures) for individuals with I/DDs, intellectually disabled individuals are likely to have a higher risk severity score than potential candidates that are nondisabled. Much like the utilization of the Sequential Organ Failure Assessment Score (SOFA) throughout the implementation of mass critical care guidelines for COVID-19, a standardized evaluation tool that is not developed on a discriminatory basis and facially neutral may, nevertheless, in its application, have a desperate and discriminatory effect on intellectually disabled persons.[45]

Organ transplantation: denials of eligibility

Transplant teams and its transplant physicians have broad discretion and authority to accept or deny an individual for solid organ transplantation. While the intended goal for listing an individual is to maximize the benefits of a viable organ, eligibility decisions compete against other legitimate interests (e.g., rates of transplant success for accreditation).[46] National policies, guidance from professional organizations, and transplant center procedures inform a transplant team's eligibility decisions. Still, transplant teams may consider additional factors beyond established eligibility criteria.[47] I/DDs, as mentioned above, pose a complex problem for transplant center eligibility policies and procedures, because a disability may be a legitimate contraindication for transplant eligibility or a discriminatory mechanism that excludes otherwise eligible intellectually disabled individuals from the national pool of organ transplant candidates.[48] However, the utilization of an I/DD as the sole basis for denying an otherwise eligible individual the life-saving medical benefits of an organ transplant constitutes unjustified pure discrimination that is violative of federal (and state) law.[49]

There is some inconsistency in both the definition of an I/DD and its use as a relative or absolute contraindication for organ transplant eligibility among transplant centers.[50] The American Association on Intellectual and Developmental Disabilities published established standards for diagnosis of I/DDs, which are intended to characterize, understand and classify the different types of I/DDs .[51] But despite these existing professional guidelines, variance among transplant centers' measures for levels of I/DD exists.[52] An early 1993 study by Professors James Levenson and Mary Ellen Olbrisch demonstrated that of 411 transplant centers, 25% of transplant centers considered an IQ ranging from 50 to 70 would be an absolute contraindication for cardiac transplantation, while 59% used the same IQ measure as a relative contraindication for cardiac transplantation.[53] Empirical data suggests that the presence of an I/DD

[43]Maldonado et al., *supra* note 33, at 125.

[44]*Id.* at 127.

[45]*See* Laura Guidry-Grimes et al., *Disability Rights as a Necessary Framework for Crisis Standards of Care and the Future of Health Care*, 50 Hastings Ctr. Rep. 28, 29 (2020).

[46]Statter et al., *supra* note 29, at 2.

[47]Nat'l Council on Disability, *supra* note 14, at 26.

[48]Richards, *supra* note 8, at 153.

[49]Hoffman, *supra* note 8, at 152; Nat'l Council on Disability, *supra* note 14, at 39, 50; Statter et al., *supra* note 29, at 3, 6.

[50]Statter et al., *supra* note 29, at 3; Richards, *supra* note 8, at 164.

[51]Christopher Richards et al., *Use of Neurodevelopmental Delay in Pediatric Solid Organ Transplantation Listing Decisions: Inconsistencies in Standards Across Major Pediatric Transplant Centers*, 13 Pediatric Transplantation 843, 847 (2009); Robert L. Shalock et al., Intellectual Disability: Definition, Classification, and Systems of Supports (12th ed. 2021).

[52]Shalovk et al., *supra* note 52.

[53]Mary Ellen Olbrisch & James L. Levenson, *Psychosocial Assessment of Organ Transplant Candidates: Current Status of Methodological and Philosophical Issues*, 36 Psychosomatics 236, 238 (1995); Ari Ne'eman et al., Health Resources & Serv. Admin., https://ww.organdonor.gov/statistics-stories/statistics.html (last updated Jan. 2019); Hoffman, *supra* note 8, at 152.

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continues to influence selection decision and practices.[54] One study evidenced that 85% of major pediatric transplant centers utilize "mental retardation" as a criterion for listing decisions.[55] Another study surveying major pediatric transplant centers demonstrated that of the 50 transplant programs from different UNOS regions, 43% "always" or "usually" considered a child's neurodevelopmental status when determining eligibility for transplantation.[56] Notably, 38% of respondents in the same study reported that the transplant center did not list an otherwise eligible individual for transplant because of the individual's neurodevelopmental status.[57] Overall, the empirical data consistently illustrates a wide variance among pediatric and adult transplants centers in measuring levels of I/DDs and the appropriate use of I/DD in eligibility decisions.

Despite a shift in national perspectives of the abilities of intellectually disabled individuals,[58] disability-based eligibility decisions persist. A 2008 study evaluating pediatric transplant centers' use of I/DD in the selection of transplant candidates evidenced that the degree of I/DD was a relevant factor in eligibility decisions.[59] The 2008 study found that 33% of pediatric centers always use neurodevelopmental delay in listing decisions.[60] In the same study, 21% of transplant centers surveyed indicated that "severe" delay was an absolute contraindication to transplant and 19% considered "profound" delay as an absolute contraindication for transplantation.[61] A 2013 study suggests improvement in providers' perceptions of I/DDs: 82% did not see "mild cognitive disability" as a contraindication for transplant and 42.6% did not see "moderate cognitive disability" as a contraindication for transplant.

Still, a 2013 survey of adult liver transplant centers found that 49.6% of the centers surveyed considered severe cognitive disability as an absolute contraindication for liver transplant eligibility.[62] More recent data suggests a trending improvement of transplant centers' usage of cognitive and intellectual disability as a contraindication to transplant. Similar to the Levenson and Olrisch study referenced above, a 2020 survey of adult and pediatric heart, kidney, liver, and lung transplant programs asked whether the transplant center considered intellectual disability as an absolute, relative, or irrelevant contraindication for transplant eligibility.[63] Of the transplant centers surveyed, only three centers viewed mild cognitive and intellectual disability as an absolute contraindication to organ transplant eligibility.[64] However, 24.8% of transplant centers still consider severe cognitive and

[54]Nat'l Council on Disability, *supra* note 14, at 30.

[55]Emma Samelson-Jones et al.*Cardiac Transplantation in Adult Patients with Mental Retardation: Do Outcomes Support Consensus Guidelines?,* 53 Psychosomatics 133, 135 (2012).

[56]Richards et al., *supra* note 52, at 846.

[57]*Id.* at 848.

[58]Hoffman, *supra* note 8, at 155; Richards, *supra* note 8, at 164.

[59]Richards et al., *supra* note 52, at 847; Nat'l Council on Disability, *supra* note 14, at 31; Statter et al., *supra* note 29, at 3.

[60]Statter et al., *supra* note 29, at 3.

[61]*Id.*

[62]Katharine Secunda et al., *National Survey of Provider Opinions on Controversial Characteristics of Liver Transplant Candidates*, 19 Liver Transplantation 395, 399 (2013); Anji Wall et al., *Genetic disease and intellectual disability as contraindications to transplant listing in the United States: A survey of heart, kidney, liver, and lung transplant programs*, 24 Pediatric Transplantation 1, 2 (2020).

[63]Wall et al., *supra* note 63, at 2.

[64]*Id.* at 7. While the study evidences a significant improvement transplant centers' perceptions of cognitive and intellectual disability as an absolute contraindication, the data suggests that of the 335 participating transplant centers, 213 transplant centers considered mild cognitive and intellectual disability as a relative contraindication for transplant eligibility. At first glance, the data may not seem controversial. However, the study leaves a question open: What are the bases for a transplant center's determination that a cognitive and intellectual disability is a relative contraindication for a potential candidate? Considering the lack of standardized guidelines, it is reasonable to imagine that unfavorable biases related to intellectually disability could have negatively influenced a transplant center's determination that a mild intellectual disability is relative contraindication for a specific potential candidate. The determination that a mild cognitive and intellectual disability is relative contraindication for a specific candidate could also be the effect of the desperate impact that arises from the use of standardized psychosocial evaluation tools.

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intellectual disability as an absolute contraindication for organ transplant eligibility and listing.[65] While some data demonstrates improvements in evaluations of intellectually disabled persons for solid organ transplantation, some professional medical organizations still consider an I/DD as a contraindication.[66] The variance in definition of I/DD among transplant centers and its use as a medical or psychosocial contraindication for transplant promotes discriminatory evaluation practices that unfairly and disproportionately exclude otherwise qualified individuals from being listed on the national waitlist.

The view that I/DDs are a relative or absolute contraindication is suggestive of implicit and presumptive biases that are unfavorable toward individuals with I/DDs.[67] Instances of discrimination could stem from physicians' unrecognized biases of disabled individuals.[68] Even if unrecognized, unfavorable biases have deleterious consequences for intellectually disabled individuals' accessibility to organ transplantation and other transplant-related services.[69] A physician's espousal of disability-related stereotypes could disproportionately exclude intellectually disabled persons from the national organ transplant system, which short-circuits the balance the system should strive to strike between the ethical principles of justice and utility. Long-standing misconceptions that accompany intellectual disability are often cited as "objective" justifications for declining transplant eligibility: (1) patient and graft survival, (2) reduced quality of life, and (3) nonadherence.[70]

Patient and graft survival

The overarching utilitarian goal of solid organ transplantation emphasizes the "maximum benefit for all transplants"[71]—therefore, the ethical principle of utility—and aims to maximize the benefit of an organ transplant, ultimately directing viable organs away from potential recipients who will not derive maximum medical benefit from the transplant, nor maximize a net overall societal good.[72] But utilizing patient and graft survival as the sole basis for eligibility decisions could undermine the equitable distribution of a scarce resource by directing viable organs toward one particular patient population.[73] Undoubtedly, the ethical duty of stewardship—an ethical duty focused on utilizing limited medical resources to preserve and promote communal health—imposes an affirmative obligation on transplant centers to consider patient and graft survival when making eligibility decisions.[74] However, a priori denials of eligibility for intellectually disabled persons focused on patient and graft survival assume that this class of individuals will not obtain the same number of life-years or quality-adjusted life years as other non-disabled individuals because of other existing comorbidities.[75]

[65] *Id.* The authors noted that when compared to the results of 1993 study conducted by Levenson and Olrisch, there is a notable improvement in the percentage of transplant centers not considering several intellectual disability as an absolute contraindication for heart (37.2% compared to 74.4%), liver (22.4% compared to 45.7%) and kidney (11.8% compared to 24.0%) transplant centers.

[66] Nat'l Council on Disability, *supra* note 14, at 38.

[67] Statter et al., *supra* note 29, at 3.

[68] Iezzoni et al., *supra* note 26, at 303.

[69] *Id.*

[70] Nat'l Council on Disability, *supra* note 14, at 39-40; Frank, *supra* note 20, at 105; Statter et al., *supra* note 29, at 22-23; Chen et al., *supra* note 14, at 2010.

[71] *OPTN/UNOS Ethics Committee General Considerations in Assessment of Transplant Candidacy*, Organ Procurement and Transplantation Network, https://optn.transplant.hrsa.gov/resources/ethics/general-considerations-in-assessment-for-transplant-candidacy/ [https://perma.cc/H2SE-9C3D] (last visited June 17, 2021).

[72] Statter et al., *supra* note 29, at 4; Nat'l Council on Disability, *supra* note 14, at 38. While this author notes philosophical disagreements about the definition of "maximum benefit," those discussions are outside the scope of this Article.

[73] *See* Lainie Friedman Ross, *The Ethics of Organ Transplantation in Persons with Intellectual Disability*, 235 J. Pediatrics 6, 7 (2021) (proposing that one implication of quality-of-life arguments could direct available organs to middle-aged white males of higher socioeconomic status because data evidence that this group has longer graft and patient survival.)

[74] *Id.*; *see also*, Statter et al., *supra* note 29, at 3-4.

[75] *See* Ross, *supra* note 74, at 5.

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In fact, available empirical data indicates that patient and graft survival is similar between individuals with and without an I/DD.[76] Several studies evidence similar rates of patient and graft survival between transplant recipients with chromosomal abnormalities (e.g., Down Syndrome) and transplant recipients without a genetic disease.[77] Recognizing that an I/DD may be independent of a genetic disease, other studies evaluating an I/DD of any origin share similar results.[78] These studies underscore that existing comorbidities of a transplant candidate with an I/DD should be weighed in a similar manner to the existing comorbidities of a person who is not intellectually disabled. Similarly, existing data supports the inclusion of individuals with I/DDs within the national pool of transplant candidates instead of categorical exclusions of intellectually disabled persons. Some commentators argue that a pre-defined minimal threshold of expected life-years respective to each organ system should be equally applied to individuals with and without I/DDs.[79] Potential solutions aside, a transplant center is legally required to evaluate existing comorbidities, whether associated with an I/DD (or not), and its potential impact on transplant candidacy on an individual basis.

Quality of life concerns

Some argue that individuals with I/DDs should be excluded from the national waitlist because individuals with I/DDs do not enjoy a comparable quality of life (QOL) to non-disabled individuals. As in Amelia's case, the underlying assumption is that an organ transplant for an individual with an I/DD would not enhance the individual's QOL, and that therefore, the recipient would not derive as much benefit from the medical intervention as would a recipient without an I/DD.[80] The World Health Organization defines QOL as an "[individual's] perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."[81] The utilization of QOL as a unique consideration for determining transplant candidacy for an individual with I/DD is problematic when transplant teams make value-laden judgments about QOL based on widely-accepted societal benchmarks and standards.[82] A recent study evaluating physicians' biases about disabled individuals evidenced that 82.4% of physicians who participated in the study believe that individuals with significant disability have a "worse" quality of life than nondisabled persons.[83]

These biased presumptions about QOL are worrisome because ample empirical evidence firmly establishes a "disability paradox:" individuals with disabilities rate their QOL higher than do physicians, healthcare professionals, and families members of disabled persons.[84] The gaps in attitudes about disability result from disproportionate focus on changes in lifestyle without giving attention to the opportunities for and types of adaptation that arises from disability.[85] "Ableist" assumptions—assumptions that rate an individual's social value based on her physical, mental, and sensory capabilities—undervalue the QOL of intellectually disabled persons.[86] These types of assumptions have subsequent

[76]Nat'l Council on Disability, *supra* note 14, at 39; Chen et al., *supra* note 14, at 2010-11; Statter et al., *supra* note 29, at 3; Wall et al., *supra* note 63, at 5,8. Note that Empirical data evaluating patient and graft survival for transplant recipients with an I/DD that is genetic in origin versus those with an I/DD that is nongenetic in origin remains sparse.

[77]Wall et al., *supra* note 63, at 5,8.

[78]Nat'l Council on Disability, *supra* note 10, at 39; Chen et al., *supra* note 14, at 2010-11; Statter et al., *supra* note 29, at 3; Wall et al., *supra* note 63, at 5,8.

[79]Ross, *supra* note 74, at 5.

[80]*Id.*

[81]The WHOQOL Group, *The World Health Organization Quality of Life Assessment (WHOQOL): Position Paper from the World Health Organization*, 41 Soc. Sci. Med. 1403, 1405 (1995).

[82]Chen et al., *supra* note 14, at 2012; Aaron Wightman et al., *Fairness, Severe Intellectual Disability, and the Special Case of Transplantation*, 22 Pediatric Transplantation, Aug. 2018 at 3.

[83]Iezzoni et al., *supra* note 26, at 300.

[84]Iezzoni et al., *supra* note 26, at 304; Statter et al., *supra* note 29, at 3; Wightman et al., *supra* note 83, at 3.

[85]Emens, *supra* note 16, at 1392-93.

[86]Dorfman, *supra* note 28, at 199-200.

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negative implications for a transplant physician's understanding of improvements in an intellectually disabled person's QOL that are derived from solid organ transplantation.[87]

Nonadherence concerns

Nonadherence is another concern proffered as a justification for excluding individuals with I/DDs from the qualifying pool of eligible transplant candidates. The nonadherence argument posits that an intellectually disabled individual's inability to understand complex medical regimens, including multiple medications and recurring doctor's appointments, will *always* result in nonadherence to post-transplant responsibilities and treatment. The nonadherence argument incorrectly assumes that individuals with I/DDs do not have strong and well-established support systems to ensure post-transplant adherence.[88] Supportive services provided for by federal and state welfare (e.g., Medicaid) and entitlement programs are an integral part of a larger support system that help individuals with I/DDs meet their daily needs and actively participate in the community.[89] Different jurisdictions' supported decision-making statutes—laws that permit a disabled individual to enter into an agreement with another person for purposes of assisting with decision-making—provide additional safeguards and protections aimed at ensuring that a disabled individual can understand the information being presented and communicate her choice.[90] A supporter, a person that helps the disabled person engage in decision-making, is particularly helpful during the organ transplantation evaluation process given the complex medical information that providers and other allied healthcare professionals present to potential candidates during the informed consent process. In addition to federal and state protections, a potential transplant candidate may have individualized support structures tailored to her specific needs. For example, family members may participate in clinical appointments for purposes of helping an individual with an I/DD communicate with providers and other healthcare professionals via adaptive technologies.

Exclusion on the grounds of nonadherence is particularly troubling given the evidentiary indication that individuals with I/DDs do not pose a significantly higher risk of nonadherence than non-disabled individuals.[91] Given the wide range, types, and degrees of intellectual disabilities, some individuals with I/DDs will require additional (and in some cases, intensive) support to adhere to post-transplant regimens.[92] This Article does not suggest that the lack of social support or nonadherence are irrelevant evaluative criteria: social support is a well-studied predictive value of transplant success for individuals with or without an I/DD.[93] Rather, anticipated concerns about nonadherence alone cannot serve as an

[87]Statter et al., *supra* note 19, at 5.

[88]Chen et al., *supra* note 14, at 2011-12; *see* Ross, *supra* note 74, at 5; Statter et al., *supra* note 29, at 5.

[89]Chen et al., *supra* note 14, at 2011-12.

[90]*See CPR Supported Decision-Making: Frequently Asked Questions*, Ctr. for Pub. Representation, https://supporteddecisions.org/about-supported-decision-making/frequently-asked-questions/ [perma.cc/YVU3-S7Q3] (last visited Dec. 31, 2022); *see also U.S. Supported Decision-Making Laws,* Ctr. for Pub. Representation, https://supporteddecisions.org/resources-on-sdm/state-supported-decision-making-laws-and-court-decisions/ [perma.cc/P454-7UXM] (last visited Jan. 9, 2023). For example, Subchapter B, Section 1357.051 of the Texas Estates Code permits a disabled individual to authorize the support to:

> provide supported decision-making, including assistance in understanding the options, responsibilities, and consequences of the adult's life decisions, without making those decisions on behalf of the adult with a disability; 2) … assist the adult in accessing, collecting, or obtaining information that is relevant to a given life decision, including medical, psychological, financial, educational, or treatment records, from any person; 3) assist the adult with a disability in understanding the information described by Subdivision (2); and 4) assist the adult in communicating the adult's decisions to appropriate persons.

Tex. Est. Code Ann. §1357.051 (West 2015).

[91]*Id.*; Chen et al., *supra* note 14, at 2011-12.

[92]Nat'l Council on Disability, *supra* note 14, at 40; Chen et al., *supra* note 14, at 2011-12.

[93]Bui et al., *supra* note 33, at 4; Maldonado et al., *supra* note 33, at 126.

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appropriate basis for outright exclusion of individuals with I/DDs from the national waitlist when nonadherence is highly prevalent in other patient populations.[94]

Presumptive biases that influence the development and application of selection criteria at transplant centers result in the exclusion of individuals with I/DD from the national waitlist. The discretionary nature of selection criteria and eligibility decisions can disguise discriminatory selection practices behind a veil of clinical judgments of medical and psychosocial eligibility.[95] The absence of federal guidance of the application of existing anti-discrimination statutes to the organ transplantation evaluation process coupled with the variance in eligibility criteria at transplant centers lends itself to considerable allegations of discrimination.[96]

Applicable federal legislation: ADA and Section 504 of the Rehabilitation Act

Congress enacted the ADA as a federal mandate to end societal discrimination against individuals with disabilities by creating sweeping affirmative obligations and prohibitions for both public and private programs and services.[97] The statute notes that the discriminatory biases inherent in social culture "are a serious and pervasive problem" persisting in healthcare.[98] Federal protections are of critical importance for individuals with I/DD (and other physical disabilities) because intellectually disabled persons require access to health care services and programs for ongoing and extensive medical treatment.[99] Therefore, applicable federal statutes like the ADA and Section 504 of the Rehabilitation Act form a legislative framework that creates protections for individuals with disabilities who are denied access to medical services on the basis of disability because of inherently biased social structures that historically disadvantage—if not, altogether exclude—disabled persons from the health care system.[100]

Part II begins by outlining two applicable federal antidiscrimination statutes. It next suggests that facially neutral eligibility criteria can serve as a covert mechanism for disability-based discrimination. The last section of Part II argues that several significant shortcomings of federal legislation lessen its ability to curb disability-based discrimination against individuals with I/DDs.

Federal antidiscrimination laws and medical decision-making

A line of cases, known as the "Baby Doe" cases, may at first glance seem to undercut an argument proposing that the ADA is applicable to transplant eligibility decisions for individuals with an I/DD. The Baby Doe cases rejected challenges to medical treatment decisions to withhold life-sustaining interventions for newborns with developmental and other congenital disabilities.[101] Lower federal courts explicitly held that antidiscrimination legislation cannot challenge (and, therefore, is not applicable to) bone fide medical treatment decisions.[102]

In each of these cases, the primary issue before the court was whether a decision to withhold surgical interventions for disabled newborn babies violated federal antidiscrimination legislation. The most prominent of these cases was *United States v. University Hospital.* Baby Doe was born with spine bifida

[94]Statter et al., *supra* note 29, at 5.

[95]Frank, *supra* note 20, at 106.

[96]Richards, *supra* note 8, at 152.

[97]Mary Crossley, *Becoming Visible: The ADA's Impact on Health Care for Persons with Disabilities*, 52 Ala. L. Rev. 51, 51 (2000); Whitehead, *supra* note 18, at 482, at 1; Richards, *supra* note 8, at 163; Tran, *supra* note 17, at 635.

[98]42 U.S.C. §12101 (2006). For discussion of the statute's aims, see David Orentlicher, *Destructuring Disability: Rationing of Health Care and Unfair Discrimination Against the Sick*, 31 Harv. C.R.-C.L.L. Rev. 49, 51 (1996).

[99]Crossley, *supra* note 98, at 51.

[100]Jessica Roberts, *Health Law as Disability Rights Law*, 97 Minn. L. Rev. 1963, 1982 (2013); Richards, *supra* note 4, at 156 (quoting Orentlicher, *supra* note 99, at 53); Whitehead, *supra* note 18, at 482; *see* Hoffman, *supra* note 8, at 165.

[101]Bagenstos, *supra* note 24, at 22; United States v. Univ. Hosp., State Univ. of N.Y., 729 F.2d 144, 156 (2. Cir. 1984).

[102]*See Univ. Hosp.,* 729 F.2d at 156-57.

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and other severe birth defects.[103] Although corrective surgery was available, Baby Doe's parents opted for conservative medical management because corrective medical interventions would not improve Baby Doe's negative prognosis.[104] The Second Circuit determined that application of the "otherwise qualified" language of Section 504 of the Rehabilitation Act, ("Section 504"), "cannot be applied in the comparatively fluid context of medical treatment decisions without distorting its plain meaning."[105] The court further suggested that "it will rarely, if ever be possible to say with certainty that a particular decision was 'discriminatory'" when the treatment decision was "based on a 'bona fide medical judgment.'"[106] To support its conclusion, the court concluded that Congress did not intend for Section 504 to apply to medical treatment decisions.[107] Under this line of reasoning, a plaintiff's claim that a disability-based denial of transplant eligibility violates the ADA and other antidiscrimination legislation would almost certainly fail.

The Supreme Court would confront the Baby Doe discrimination question in *Bowen v. American Hospital Association.* In *Bowen*, the central question was whether Section 504 authorized regulations governing the provision of medical treatment for handicapped infants. While the *Bowen* opinion rested upon the reasoning in *University Hospital*, it diverged from its ultimate conclusion. That is, the court's final ruling in Bowen that the withholding of medical treatment did not violate Section 504 of the Rehabilitation Act turned on the narrow issue of parental consent: "[W]ithout the consent of the parents…the infant is neither 'otherwise qualified' for treatment nor has he been denied care 'solely by reason of his handicap."[108] The Supreme Court left open the possibility that medical treatment decisions, even if based on bone fide medical judgment, could come within the scope of antidiscrimination prohibitions: "it is not necessary to determine that whether § 504 ever applies to individual medical treatment decisions."[109] Accordingly, both *University Hospital* and *Bowen* are unsuitable bases for a legal claim that antidiscrimination statutes are not applicable to medical treatment decisions.

The Supreme Court would later undercut the underlying premise of *University Hospital.*[110] In *Pennsylvania Department of Corrections v. Yeskey*, a State prison inmate was denied admission to a boot camp program due to the inmate's history of hypertension.[111] The inmate sued the Pennsylvania Department of Corrections alleging discrimination under the ADA.[112] The decision in *University Hospital* rested on the premise that Congress did not anticipate that Section 504 (or other antidiscrimination statutes) would apply to medical treatment decisions. In *Yeskey*, the state argued that the language of Title II "does not mention prisons or prisoners," and therefore, Congress did not "'intend that the ADA would be applied to state prisons.'"[113] The Supreme Court disagreed. It held that the Title II's antidiscrimination coverage extends to incarcerated individuals within the state's prison system.[114] From the Court's perspective, the state's argument was irrelevant because the application of a federal statute to "'situations not expressly anticipated by Congress does not demonstrate ambiguity. It demonstrates breadth.'"[115] The *Yeskey* decision provides that state programs and services must adhere to the statutory prohibitions and requirements set forth by the ADA and other federal legislation.[116]

[103] *Id.* at 146.
[104] *Id.*
[105] *Id.* at 156.
[106] *Id.* at 157.
[107] *Id.* at 156-7.
[108] Bowen v. American Hosp. Ass'n., 476 U.S. 625, 630 (1986).
[109] *Id.* at 624.
[110] Bagenstos, *supra* note 24, at 23.
[111] Pennsylvania Dep't. of Corr. v. Yeskey, 524 U.S. 206, 208 (1998).
[112] *Id.*
[113] *Id.* at 211-12.
[114] *Id.* at 213.
[115] *Id.* at 212 (quoting Sedima, S.P.R.L. v. Imrex Co., 473 U.S. 479, 499 (1985)).
[116] *See id.* at 206, 209-10.

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After *Yeskey*, similar claims of applicability and ambiguity would not preclude the applicability of federal antidiscrimination laws to transplant eligibility decisions for individuals with I/DDs.

The conclusions in later cases, discussed in detail below, stand in stark contrast to the holding in *University Hospital.* In *Bragdon v. Abbott*, the Supreme Court determined that a dentist's refusal to perform a routine dental operation for an HIV positive patient violated Title III of the ADA.[117] In *Olmstead v. L.C.,* the Court held that the ADA requires states' health care programs and services to be compliant with the ADA's statutory requirements and prohibitions.[118] These subsequent cases recognize that the scope of the ADA reaches medical treatment decisions and, by extension, clinical determinations of transplant eligibility.

ADA and Section 504 of the Rehabilitation Act

Under the ADA, an individual is considered disabled if they have "a physical or mental impairment that substantially limits one or more major life activities."[119] A "major life activity" includes a spectrum of daily activities ranging from "caring for oneself, learning, concentrating, thinking" to more basic actives like "eating [and] sleeping."[120] A life activity is limited if the individual cannot perform or complete the task when compared to the general population.[121]

Title II and Section 504

Generally, Title II of the ADA ("Title II") prohibits disability-based discrimination by requiring public entities to make reasonable modifications that enable qualified individuals to participate in programs and services provided by the public entity.[122] A hospital is a public entity under Title II when it is affiliated with a state or county hospital or a state university. [123] Given that Title II's protections extend to all operations of the public entity, transplantation services offered at transplant centers fall within the scope of Title II.[124]

Section 504 of the Rehabilitation Act, a sister statute to Title II, imposes similar affirmative obligations on entities receiving federal funding.[125] Most hospitals and transplant centers receive some form of federal funding (e.g., Medicare), so any part of a program or service that receives federal funding remains subject to Section 504.[126]

For purposes of Title II, a hospital or transplant center cannot discriminate against a qualified individual on the basis of disability if the potential candidate comes within the statutory definition of disability and—with or without reasonable modifications—meets the essential eligibility requirements of a program or service.[127] In *Olmstead*, two women who were voluntarily admitted at the state-run Georgia's Regional Hospital filed a discrimination suit after remaining involuntarily institutionalized despite multiple physician recommendations that the two women receive mental health treatment in a community setting. Involuntarily retaining the two women in a segregated environment constituted discrimination under Title II of the ADA. In its decision, the *Olmstead* Court opined that Title II and Section 504 protections contemplate intellectual disabilities.[128] Assuming that individuals with I/DD are

[117]Bagenstos, *supra* note 24, at 23.
[118]*See id.*
[119]42 U.S.C. §12102(1) (2006).
[120]42 U.S.C. §12102(2) (2006).
[121]Richards, *supra* note 8, at 163.
[122]Richards, *supra* note 8, at 176; Whitehead, *supra* note 18, at 482; *see also* Nat'l Council on Disability, *supra* note 14, at 47; Tran, *supra* note 17, at 635-36.
[123]Nat'l Council on Disability, *supra* note 14, at 47; Richards, *supra* note 8, at 163.
[124]Nat'l Council on Disability, *supra* note 14, at 47.
[125]Nat'l Council on Disability, *supra* note 14, at 47; *see* Frank, *supra* note 20 at 106.
[126]Nat'l Council on Disability, *supra* note 14, at 48.
[127]42 U.S.C. §12111(8), 12102(1); Richards, *supra* note 8, at 163.
[128]Tran, *supra* note 17, at 637.

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qualified individuals, transplant centers must therefore make reasonable modifications for individuals with I/DDs that ensure equal access to, and participation in, the transplant program and its other transplant-related services.[129] For example, the ADA would require a transplant center to modify the format and font text of educational materials for an individual with I/DD so that the individual can actively participate in the decision-making process, which has significant implications for informed consent.

Ultimately, the ADA's prohibition of invidious discrimination requires transplant centers to conduct individualized assessments and make reasonable modifications that support the intellectually disabled person's candidacy for solid organ transplantation.[130] Still, hospitals or transplant centers may be exempt from statutory obligations if the requested modification would fundamentally alter the nature of the program or service offered, or create an undue burden (e.g., cost) for the entity.[131]

Title III

Title III of the ADA ("Title III") prohibits public accommodations from utilizing eligibility criteria that "subjects an individual…on the basis of disability…to a denial of the opportunity of the individual…to participate in…the services…of an entity."[132] Private hospitals are a public accommodation for purposes of Title III. Thus, the anti-discriminatory mandate within Title III reaches transplantation services offered at private hospitals. [133] Title III prohibits a public accommodation from utilizing eligibility criteria that screens out or tends to screen out an individual or class of individuals from the equal use and full enjoyment of the goods or services that the entity offers.[134] A public accommodation is required to make the necessary reasonable modifications to its policies, practices, and procedures so that a disabled individual equally participates in its services or accommodations.[135]

Within the context of an evaluation of transplant candidacy for an intellectually disabled individual, a transplant center may be required under Title III to remove I/DD as an absolute contraindication for organ transplantation from its medical or psychosocial evaluative criteria. Similar to Title II, Title III contemplates reasonable modifications tailored to the disabled individual requesting an organ transplant evaluation. A public accommodation must demonstrate that the modification would fundamentally alter the nature of the service or accommodation in order to avoid Title III's antidiscrimination provision.[136]

Eligibility criteria and discrimination under the ADA

There is minimal federal guidance identifying appropriate selection criteria for transplant candidacy. Absent additional guidance or procedural safeguards, transplant teams and physicians and other interested health care professionals remain susceptible to presumptive biases that disadvantage individuals with I/DDs.[137] UNOS's Ethics Committee and other professional reports recommend that individuals with I/DDs should not be denied an evaluation for solid organ transplantation on disability grounds alone.[138] These types of position statements are valuable tools that inform the development of

[129]Nat'l Council on Disability, *supra* note 14, at 47; Richards, *supra* note 8, at 163; Whitehead, *supra* note 18, at 482.

[130]Nat'l Council on Disability, *supra* note 14, at 47; *see* Whitehead, *supra* note 18, at 491.

[131]*Id.*

[132]42 U.S.C. §12182(b)(1)(A)(i) (2006).

[133]Nat'l Council on Disability, *supra* note 10, at 47; Richards, *supra* note 8, at 163; Whitehead, *supra* note 18, at 482.

[134]42 U.S.C. §12182(a) (2006); Nat'l Council on Disability, *supra* note 14, at 47; Richards, *supra* note 8, at 163; Whitehead, *supra* note 18, at 482.

[135]42 U.S.C. §12182(b)(2)(A)(ii) (2006); Nat'l Council on Disability, *supra* note 14, at 48; Whitehead, *supra* note 18, at 482.

[136]42 U.S.C. §12182(b)(2)(A)(ii) (2006).

[137]Statter et al., *supra* note 29, at 3.

[138]Cmty. Ethics Comm., Cmty. Voices in Med. Ethics, Inc., Organ Transplant Recipient Listing Criteria, 14 (2014), https://www.childrenshospital.org/sites/default/files/media_migration/3a6cb042-e46a-41a3-a1e1-1d48744ab4fe.pdf [perma.cc/5JV9-JNPS]; Frank, *supra* note 20, at 103. Ethics opinions are valuable tools that help define the boundaries

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local, state, and federal transplant-related policies and practices. But position statements lack enforcement mechanisms, relying only on voluntary adherence from transplant centers. As such, ethical position statements alone do not incentivize or legally require transplant centers to modify its selection criteria as some transplant centers still list I/DDs as a relative or absolute contraindication for organ transplantation.[139] And as discussed above, available empirical data shows that compliance rates and patient and graft survival rates of individuals with I/DDs are similar to compliance rates and patient and graft survival rates of individuals without I/DDs.[140] Thus, the inclusion of intellectual disability as an absolute contraindication to transplant eligibility in selection criteria is likely violative of the ADA because an otherwise qualified individual is denied eligibility and consequently, access to the whole spectrum of transplantation services, on the basis of disability alone.[141]

Listing I/DDs as an absolute contraindication to organ transplantation promotes the categorical exclusion of a class of individuals from transplantation services, including an evaluation of the individual's candidacy. Determinations of individual's candidacy based on membership in a group of individuals categorically excluded from eligibility for organ transplantation subverts the central purpose of the ADA.[142] Transplant center evaluation policies and selection practices that do not require an individualized assessment of the person's eligibility for solid organ transplantation because its eligibility criteria list I/DDs as an absolute contraindication likely results in the type of disability-based discrimination prohibited by federal legislation.[143]

This Article does not intend to suggest that consideration of an I/DD as a contraindication to transplant is a violation of the ADA is *all* circumstances. Instead, the evaluation of individuals with I/DDs for organ transplantation should be conducted in the same or similar manner for individuals without I/DDs: "without presumption of contraindications to transplantation."[144] Transplant physicians may consider an I/DD as a relative contraindication to transplantation when an evaluation for transplant candidacy identifies a bona fide medical or psychosocial risk factor, specific to that individual, that is medically significant to post-transplant clinical outcomes.[145] Compliance with federal antidiscrimination mandates obligates a transplant center to perform an individualized assessment of a qualified individual's candidacy and make reasonable modifications to its policies, practices, and procedures before an official denial of eligibility for solid organ transplantation.[146]

Limitations of federal legislation

It is well-settled that the hospital services and operations, including transplant centers and its transplant physicians, are subject to the antidiscrimination mandates codified in federal law.[147] However, while current federal legislation has narrowed a physician's ability to refuse to provide medical treatment for disabled individuals, the effect of antidiscrimination legislation within the sphere of organ

of the practice of organ transplant medicine. However, these types of positions statements alone will not likely prevent discriminatory policies and practices. *Id.* at 110.

[139]Richards, *supra* note 8, at 164.

[140]Nat'l Council on Disability, *supra* note 10, at 39; Richards, *supra* note 8, at 164.

[141]Richards, *supra* note 8, at 164; *see* Crossley, *supra* note 98, at 54.

[142]Whitehead, *supra* note 18, at 491.

[143]*See* Richards, *supra* note 8, at 164; *see also,* Crossley, *supra* note 98, at 55-56.

[144]Richards, *supra* note 8, at 164.

[145]*See* Govind Persad, *Disability Law and the Case for Evidence-Based Triage in a Pandemic*, 130 Yale L.J. Forum 26, 35 (2020); Richards, *supra* note 8, at 163 (noting that a transplant center may use mental disability as a consideration if the transplant center has actual evidence that the mental disability will impact transplant recipient's ability to comply with post-transplant regimens); Tran, *supra* note 17, at 639-41. *See also* Begenstos, *supra* note 24, at 8.

[146]Nat'l Council on Disability, *supra* note 10, at 47; Richards, *supra* note 8, at 163; Whitehead, *supra* note 18, at 491.

[147]Nat'l Council on Disability, *supra* note 10, at 47-48; Tran, *supra* note 17, at 633; Whitehead, *supra* note 18, at 482.

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transplantation remains less clear.[148] Four major issues that challenge the applicability of federal antidiscrimination law to the organ transplant evaluation process include (1) underenforcement of the ADA,[149] (2) paucity of case law,[150] (3) deference to physician judgment,[151] (4) vagueness resulting from the lack of federal guidance.[152]

Underenforcement and claim scarcity

Titles II and III of the ADA are underenforced, and one potential culprit is the lack of claims filed with the Office of Civil Rights or another appropriate administrative agency. The scarcity of claims could be premised by a myriad of factors. For example, a potential candidate may not file a claim because she does not know that she was subject to disability-based discrimination violative of federal law. Commentors identify a major obstacle to optimal enforcement: an ineffective and weak public enforcement mechanism.[153] The Department of Justice (DOJ), as the public avenue for enforcement of the ADA, has assigned only a small number of lawyers assigned to disability rights enforcement whose scope of enforcement responsibility extends to both state and local governments and private businesses.[154] As a consequence, private enforcement is a necessary element of the ADA's effectiveness. That is, the ADA's ability to curtail and eliminate disability-based discrimination remains largely dependent upon individual lawyers in need of profit to sustain their practices.[155]

While private enforcement is the primary avenue of enforcement, the limited remedies available under Title II and Title III disincentivize lawyers from litigating these types of cases. Under Title II, private plaintiffs may generally sue for compensatory damages.[156] To be entitled to compensatory damages, courts have generally required that private plaintiffs prove discriminatory intent.[157] Given the courts' deference to physicians' determinations of transplant eligibility, discriminatory intent may be difficult for the private plaintiff to prove. Consider a case in which a transplant center denies an individual eligible for transplant because the transplant center's psychosocial criteria lists a severe intellectual disability as an absolute contraindication to transplant. A court may be hesitant to second guess the transplant center's eligibility criteria and the transplant physician's medical judgment. In this case, discriminatory intent could be masked, or even legitimized, behind a denial of transplant eligibility based on the transplant center's psychosocial criteria.

Unlike Title II, Title III affords private litigants only equitable relief and attorney's fees as an exclusive source of compensation.[158] Whereas private counsel with fee-paying clients can be paid for expended hours on cases won or lost, plaintiff's counsel are entitled to payment from the hours expended on cases they have won.[159] The statutory compensation scheme alone discourages lawyers from taking on disability-discrimination cases when incoming profits are necessary to maintain private practice.

[148] *See* Ari Ne'eman et al., *Organ Transplantation and People with I/DD: A Review of Research, Policy and Next Steps*, policy brief, Autistic Self-Advoc. Network, https://autisticadvocacy.org/wp-content/uploads/2013/03/ASAN-Organ-Transplantation-Policy-Brief_3.18.13.pdf (2013).

[149] Leslie Lee, *Giving Disabled Testers Access to Federal Courts: Why Standing Doctrine is Not the Right Solution to Abusive ADA Litigation*, 19 Va. J. Soc. Pol'y & L. 319, 339 (2011); Casey L. Raymond, *A Growing Threat to the ADA: An Empirical Study of Mass Filings, Popular Backlash, and Potential Solutions Under Titles II and III*, 18 Tex. J. on C.L. & C.R. 236, 252 (2013).

[150] Nat'l Council on Disability, *supra* note 14, at 49.

[151] Frank, *supra* note 20, at 106; Whitehead, *supra* note 18, at 491.

[152] Nat'l Council on Disability, *supra* note 14, at 49; Tran, *supra* note 17, at 637.

[153] Samuel R. Bagenstos, *The Perversity of Limited Civil Rights Remedies: The Case of "Abusive" ADA Litigation*, 54 UCLA L. Rev. 1, 9 (2006); Lee, *supra* note 151, at 346.

[154] *Id.*

[155] Bagenstos, *supra* note 155, at 9; Lee, *supra* note 150, at 340; Raymond, *supra* note 150, at 251.

[156] Raymond, *supra* note 151, at 251.

[157] *Id.*

[158] Bagenstos, *supra* note 155, at 10; Lee, *supra* note 150, at 321; Raymond, *supra* note 150, at 252.

[159] Bagenstos, *supra* note 155, at 10.

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Paucity of case law: lack of expediency clause

One noted shortcoming of federal legislation is the ambiguity surrounding the relevance and applicability of these statutes to the initial stages of the organ transplant process. [160] The lack of clear resolution is due, in part, to the scarcity of litigation that strikes at the core issue: the nexus between current anti-discrimination legislation and transplant center selection practices.[161] Lots of time is required to thoroughly litigate discrimination claims in federal court.[162] Applicable federal statutes do not permit or mandate a court to expedite review of a claim that challenges discriminatory selection criteria and procedures. The potential for a worsening disease trajectory may deter some intellectually disabled individuals from filing a claim in federal court. Moreover, advanced disease may cause an intellectually disabled individual to become too ill to pursue a federal discrimination claim based on a denial of eligibility.[163] And if a change in clinical status poses a high risk for poor clinical post-transplant outcomes, the individual will be medically incompatible for solid organ transplant, which may render the discrimination claim moot.[164]

Just fourteen states have enacted legislation prohibiting disability-based discrimination in the evaluation of transplant candidacy.[165] Of the fourteen that have passed state-level anti-discrimination legislation, a smaller number of states explicitly prohibit discrimination on the basis of an intellectual disability. [166] The widespread legislative inattention—federal and state alike—to intellectual disability-based discrimination leaves a majority of the intellectually disabled population left unprotected. To offset the extended period needed to litigate claims in federal courts, some states, like California, have included an expediency clause that provides for the court's ability to prioritize claims of discrimination for those seeking remedy under the statute.[167] It remains unclear if the time-sensitive nature of eligibility decisions and potential for acute medical decompensation undercuts the effectiveness of these types of clauses.

Vagueness: lack of federal guidance

There is no question that federal anti-discrimination legislation is applicable to medical decision-making,[168] so it is somewhat curious that executive and administrative agencies do not provide more specific guidance describing what constitutes discrimination throughout the entirety of the organ transplant evaluation process. [169] The sizeable gap in federal guidance is not for lack of authority:

> [The Department of Justice] has authority to interpret and enforce Titles II and III of the ADA. Under Executive Order 12250, DOJ is also authorized to coordinate with consistent implementation of Section 504 of the Rehabilitation Act (Section 504) across Federal Government. HHS has the authority to investigate complaints related to 'the provision of health care and social services' under Title II of the ADA. HHS also has authority to promulgate regulations, issue technical assistance

[160]Crossley, *supra* note 98, at 56; Frank, *supra* note 20, at 106-07. Another speculated reason for the dearth of a case law on the subject is that the individual with I/DD seeking a transplant may not be aware that she has been subject to illegal discrimination. Assuming awareness of a potential remedy, litigation is expensive, and some individuals may not have the funds to pursue litigation to its completion.

[161]Crossley, *supra* note 98, at 56; Frank, *supra* note 20, at 106; Nat'l Council on Disability, *supra* note 14, at 50.

[162]Nat'l Council on Disability, *supra* note 14, at 50.

[163]*Id.*

[164]Nat'l Council on Disability, *supra* note 14, at 50 (describing anecdotal testimony that Leif O'Neil was denied a heart transplant because of his autism. O'Neil was too sick to pursue a federal claim of discrimination).

[165]Hoffman, *supra* note 8, at 157; Nat'l Council on Disability, *supra* note 14, at 57; Nat'l Down Syndrome Soc'y, *supra* note 12; Tran, *supra* note 17, at 637.

[166]Frank, *supra* note 20, at 103; Nat'L Council on Disability, *supra* note 14, at 57.

[167]Frank, *supra* note 20, at 103.

[168]Nat'l Council on Disability, *supra* note 14, at 51-53.

[169]Frank, *supra* note 20, at 102; Nat'l Council on Disability, *supra* note 14, at 51-53.

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> and guidance, and enforce the obligations of Section 504 with respect to entities receiving federal funding from HHS and HHS programs and activities.[170] [citations omitted]

Despite a congressional petition to the Health and Human Services (HHS) Office of Civil Rights (OCR) for federal guidance on the issue, HHSOCR has remained silent.[171] Transplant physicians and transplant teams are thus unaware of the applicability of antidiscrimination legislation to eligibility decisions.[172] In other words: in all likelihood, at least some practices and procedures at transplant centers are not compliant with federal mandates to make reasonable modifications to policies and procedures to persons with I/DDs.[173]

Federal guidance may motivate transplant centers to make changes to policies and procedures that provide for equitable access to organ transplantation for individuals with I/DDs. Recall that some states have clarified the ambiguity of federal statutes by passing legislation that prohibits discrimination on the sole basis of disability vis-a-vie the proscription of appropriate evaluation criteria and the weighing of such criteria in eligibility decisions.[174] Again, disability-based discrimination can result from an intentional act to mask it using neutral eligibility criteria or the influence of unconscious processes on good-faith eligibility decisions.[175] The nature of disability-based discrimination remains covert, which renders state counterparts to federal legislation equally as difficult to enforce.

Aside from enforcement issues, the scope and content of state-level statutes vary.[176] For example, some states' statutory protections do not extend to individuals with I/DDs.[177] The disparity among state legislation, coupled with conflict of law principles, has the potential to disrupt the "utility versus justice equation" embedded within a national transplant system.[178] The national equation attempts to balance the maximization of transplant success (i.e., utility) by directing organs to medically compatible individuals and an equitable distribution of available organs (i.e., justice) among a national pool of transplant candidates. Absent clarifying guidelines for transplant medicine, transplant teams and transplant physicians are left to self-regulate against a priori eligibility decisions based on implicit and negative biases that accompany intellectually disabled individuals.[179]

Deference to physician judgment

Given courts' deference to a physician's clinical judgments, the ADA's broad sweeping protections fall short of its intended goal to eliminate disability-based discrimination within the context of health care.[180] In *University Hospital*, Baby Jane Doe was born with spina bifida, microcephaly, and hydrocephaly. Physicians informed Baby Jane Doe's parents that corrective surgeries could improve her prognosis. Baby Jane Doe's parents elected to forgo surgery. After University Hospital refused to turn over Baby Jane Doe's medical records, the DOJ filed suit to obtain the medical records to assess whether Baby Jane Doe was subject to disability-based discrimination. The Second Circuit Court of Appeals affirmed the dismissal of the claim for discrimination under Section 504 where the hospital, who at the directions of the child's parents, did not perform corrective surgeries for Baby Doe.

The court's reasoning suggested that applicable federal statutes would require physicians to perform medical interventions unrelated to disability. As in *University Hospital*, a physician's refusal to provide or

[170] Nat'l Council on Disability, *supra* note 14, at 51.
[171] Hoffman, *supra* note 8, at 157.
[172] Frank, *supra* note 20, at 106; Nat'l Council on Disability, *supra* note 14, at 51.
[173] Nat'l Council on Disability, *supra* note 14, at 54.
[174] *See supra* note 12.
[175] *See supra* note 45, 46.
[176] Nat'l Council on Disability, *supra* note 10, at 57-60; Richards, *supra* note 8, at 168.
[177] Frank, *supra* note 20, at 107 (noting that of the fourteen states with enacted antidiscrimination legislation, only California and New Jersey outlaw discrimination on the basis of intellectual disability).
[178] *Id.*
[179] *See* Frank, *supra* note 20, at 56.
[180] Whitehead, *supra* note 18, at 484.

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offer medical treatment may not be violative of federal mandates when the disability will limit the individual's ability to benefit from the proposed treatment.[181] The "bona fide medical judgment" standard focuses on the physician's determination of whether a patient's disability will limit the anticipated benefits of the proposed medical treatment.[182] So long as the treatment is related to the disability and the disability imposes limitation on the anticipated benefits from the treatment, then the physician may avoid the affirmative obligations of antidiscrimination legislation.[183]

An important question emerges from this rationale: is any disability-related limitation, regardless of degree or severity, sufficient to satisfy the standard? This question has not been formally litigated. The standard also erroneously assumes that the physician's determination contemplates only her technical medical expertise absent any value-laden considerations of social worth. This assumption alone is problematic when available empirical evidence suggests that physicians are susceptible to implicit biases that disfavor individuals with disabilities.[184]

Existing co-morbidities and medical complications are legitimate disability-related medical variables that may preclude transplant candidacy.[185] In light of the limited availability of organs, clinical expertise is necessary to prevent the loss of a viable organ due to medical complications resulting from post-transplant non-adherence.[186] It is important to preserve the integrity and autonomy of a transplant physician's medical decision-making because courts lack sufficient clinical expertise and competency to understand the complexities of solid organ transplant eligibility decisions.[187] But an accepted standard of judicial deference to a transplant physician's clinical judgments makes disability-based discrimination difficult to prove, and consequently, inappropriately insulates providers from civil liability under the ADA and Section 504.[188] Judicial hesitancy, rooted in reliance upon medical expertise as evidenced in *University Hospital*, promotes disability-based eligibility decisions, which run contrary to the language and purpose of federal antidiscrimination legislation.[189]

Proposed federal legislation: H.R. 8981

A recently submitted federal bill, H.R. 8981, attempts to fortify existing federal antidiscrimination legislation by expressly prohibiting disability-based discrimination during the entirety of the organ transplantation evaluation process and other transplant-related services. Part A highlights significant provisions of H.R. 8981 and its potential impact on curbing disability-based discrimination relating to organ transplantation. Part B discusses the anticipated advantages that H.R. 8981 offers over current federal antidiscrimination mandates. This Part concludes with a discussion of potential drawbacks to H.R. 8981.

H.R. 8981: The Charlotte Woodward Organ Transplant Discrimination Prevention Act

During the 116th Congress, Representatives Jaime Herrera Beutler and Katie Porter introduced H.R. 8981, entitled The Charlotte Woodward Organ Transplant Discrimination Prevention Act (the

[181] *Id.*

[182] *Id.*

[183] *Id.*

[184] Statter et al., *supra* note 29, at 3; *see* Iezzoni et al., *supra* note 26, at 303.

[185] Crossley, *supra* note 98, at 55; Frank, *supra* note 20, at 106-07; Persad, *supra* note 146, at 35; *see* Bagenstos, *supra* note 24, at 8.

[186] Frank, *supra* note 20, at 106.

[187] Crossley, *supra* note 98, at 55; Frank, *supra* note 20, at 106-07 (arguing that courts will consider only the individual circumstances of the person that is party to the case, and not the eligibility of the individual within the context of the larger pool of transplant candidates).

[188] Bagenstos, *supra* note 24, at 6; Crossley, *supra* note 98, at 56; Frank, *supra* note 20, at 108; Nat'l Council on Disability, *supra* note 14, at 50; Ari Ne'eman et al., *The Treatment of Disability under Crisis Standards of Care: An Empirical and Normative Analysis of Change over Time during COVID-19*, 46 J. Health Pol'y & L. 831, 855 (2021).

[189] Crossley, *supra* note 98, at 56.

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Act).[190] The Act is a federal bill that aims "to prohibit discrimination on the basis of mental or physical disability in cases of anatomical gifts and organ transplants."[191] The Act aims to reinforce the overarching goals of existing antidiscrimination legislation by "ensuring that a person's capacity [or perceived incapacity] to comply with post-transplant treatment requirements is not a significant reason to deny them a transplant procedure" and that "policies, practices and procedures [are made] accessible to qualified recipients with disabilities."[192]

General prohibitions and affirmative obligations

More specifically, the Act explicitly prohibits transplant centers, their transplant teams, and transplant physicians, from denying transplant services to a qualified individual on the basis of disability.[193] As discussed above, a qualified individual, for purposes of Title II, is an individual who with or without reasonable modifications meets the essential eligibility requirements of a program or service offered. Title II requires that a covered entity make reasonable modifications that ensures a qualified individual's ability to participate in the program or service offered. A public accommodation, under Title III, must make reasonable modifications that ensure that a disabled individual enjoys the full and equal enjoyment of the accommodation. The Act tailors the broader language of Title II and Title III to the organ transplantation arena. If the individual requesting a transplant who, with or without reasonable modification(s), support service(s), or the provision of auxiliary aids, meets the eligibility requirements, then the individual is a "qualified individual" under the Act.[194] The definition of disability references the definition of disability within the ADA,[195] and therefore, consistent with *Olmstead*, the scope of the Act's antidiscrimination mandate extends to intellectually disabled individuals.[196] If the Act becomes federal law, it would provide coverage to the larger national population of intellectually disabled individuals who may currently fall outside state-level antidiscrimination statutes.[197]

Like other federal statutes, the Act imposes affirmative obligations upon providers to make transplant-related services available to individuals with I/DDs. Recall that under the ADA, a covered entity may escape the ADA's affirmative obligations if the covered entity can demonstrate that the requested modification would result in an undue burden. Under the Act, if a transplant team can demonstrate that the provision of auxiliary aids and services[198] would "fundamentally alter the nature of the services being offered or result in undue burden," then the transplant team could be exempt from the Act's legal requirements.[199] For purposes of ensuring equitable selection practices, the Act would require a transplant center to acquire assistive technologies (e.g., FM listening system) unless the cost of purchasing these types of devices, for example, would create an undue burden for the transplant center. A transplant physician may consider a disability when she determines, after an individualized assessment of the potential candidate, that the intellectual disability is "medically significant to the provision of the

[190]Nat'l Down Syndrome Soc'y, *supra* note 12.
[191]H.R. Res. 8981.
[192]Nat'l Down Syndrome Soc'y, *supra* note 12.
[193]H.R. Res. 8981, §§(2)(2)(a), (3)(a)(1)-(2).
[194]*Id.*
[195]*Id.* §(2)(1)(4), (3)(d)(2).
[196]Tran, *supra* note 17, at 637.
[197]*See* Frank, *supra* note 20, at 107. Discrimination occurs when a transplant center fails to make reasonable modifications to its practices, policies, and procedures for purposes of ensuring accessibility to—and availability of—transplant-related services to disabled individuals. The Act requires that transplant centers provide accessibility services to support an intellectually disabled individual's eligibility for solid organ transplantation.
[198]H.R. Res. 8981, §(2)(2)(A)-(E) (clarifying that "auxiliary aides and services" includes qualified interpreters or other effective methods of making aurally delivered materials available to individual with hearing impairments; qualified readers, taped texts, or other effective methods of making visually delivered materials available to individuals with visual impairments; provision of information in a format that is accessible for individuals with cognitive, neurological, developmental, or intellectual disabilities; provision of supported decision-making services; and acquisition or modification or equipment or devices).
[199]*Id.* §(3)(d)(1).

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anatomical gift."[200] Ultimately, a transplant team could not deny eligibility or transplant-related services to an individual with I/DD unless the transplant physician could provide, after an individualized assessment of the individual, medically relevant justifications for denying candidacy.

Available remedies

The available remedies under the Act are intended to guarantee equitable access to organ transplantation and other transplant-related services for intellectually disabled individuals. The Act's affirmative obligations and remedies require transplant centers to evaluate an intellectually disabled individual's eligibility for transplant in the same or similar manner to organ transplant evaluations for nondisabled persons. If a plaintiff successfully challenges a disability-based denial of transplant eligibility, the Act permits a court to grant equitable and injunctive relief.[201] A court could require a covered entity to (1) make available auxiliary aids and services to the plaintiff,[202] (2) make reasonable modifications to a policy, practice, or procedure of a covered entity,[203] or (3) make facilities of the covered entity readily accessible and usable.[204] The provision of any remedy, or some combination thereof, offsets default presumptions of an intellectually disabled person's ineligibility for organ transplantation. In their application, these remedies create a single threshold of transplant eligibility for both disabled and nondisabled persons.

However, in its current form, the Act's available remedies do not protect an intellectually disabled individual from instances of *pure* discrimination. Consider a scenario in which a transplant physician performs a transplant evaluation, but deems the individual ineligible for transplant solely on the basis of the individual's I/DD. The individual successfully sues the transplant center, and the court grants injunctive relief. Even with the provision of reasonable modifications or auxiliary aids and services, a transplant physician, could still deny the potential transplant candidate on the basis of medical or psychosocial ineligibility, which makes a showing of disability-based discrimination difficult. Absent an enforcement mechanism, the Act may have little success in preventing disability-based discrimination.

HHS, as a regulatory agency, is responsible for the enforcement of Titles II and III of the ADA and Section 504 of the Rehabilitation Act.[205] As the Act passes through the legislative process, a future iteration of the Act could include language that, like current federal antidiscrimination legislation, authorizes HHS to enforce the Act and provide for additional administrative remedies.

HR 8981: foreseen benefits

The Act offers several key advantages over current federal discrimination legislation, including (1) relevance to transplant medicine, (2) expedited review, (3) mandated individualized assessment, and (4) the "medically significant" criteria.

Relevance to Transplant Medicine

Currently, hospitals with transplant programs receive minimal guidance about the applicability of the ADA to its eligibility decisions, so it oftentimes is unclear when a denial of eligibility constitutes illegal discrimination. In an effort to advance the goal of resolving the ambiguity of the applicability of antidiscrimination statutes, the Act specifically addresses discrimination within the context of the organ transplant process.[206] It requires that transplant teams make reasonable modifications to its policies, practices, and procedures to ensure that all of its transplant-related services are made available to

[200] *Id.* §(3)(b)(1). The Act does not define the term "medically significant."
[201] *Id.* §(4)(b).
[202] *Id.* §(4)(b)(1).
[203] *Id.* §(4)(b)(2).
[204] *Id.* §(4)(b)(3).
[205] Nat'l Council on Disability, *supra* note 10, at 51.
[206] H.R. 8981, §(3)(1)-(5).

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qualified individuals with I/DDs at each step of the transplant process.[207] Reasonable modifications must factor into the individualized assessment and determination of the individual's eligibility for transplant.[208]

The Act further contemplates that reasonable modifications include individuals (e.g., caregivers) who support the transplant recipient and larger support networks (e.g., community-based services).[209] Consideration of support systems permits a substitution of responsibility for post-transplant medical treatment that lessens the opportunity to utilize psychosocial risk factors (e.g., independence) as camouflage for discriminatory selection practices.[210] Identifying the types of reasonable modifications that a transplant center must make when an individual with an I/DD requests an evaluation clarifies the relevance of this and other federal anti-discrimination mandates to the initial stages of the organ transplantation evaluation process. The reasonable modification mandate provides a buffer between evidence-based eligibility decisions and discriminatory selection practices that account for the intellectual disability and accompanying negative assumptions.[211]

Expedited review

The paucity of case law litigating discrimination in the organ transplant evaluation process is, in part, due to the substantial length of time needed to litigate a claim in the federal court system.[212] The length of time either deters an individual from filing a claim or prognostic uncertainties prevent an individual from pursuing the claim to its final disposition.[213] Without providing a definite time period, the Act contains a provision that requires a federal court to advance the discrimination claim for priority review.[214] Expeditious resolution of the claim through the federal court system makes organ transplantation services more readily accessible to individuals with I/DDs.

One concern associated with expediated review is the potential for judicial infringement on a transplant physician's independent clinical determinations of a disabled individual's eligibility for organ transplant. However, the remedies do not permit a court to order a transplant physician to list an intellectually disabled individual for organ transplant, and therefore stops short of impeding upon the independent practice of transplantation medicine. The available remedies under the Act are limited: requiring reasonable modifications to policies, practices, and procedures; or the provision of auxiliary aids or services. These remedies become relevant to eligibility because physicians must consider the reasonable modifications made to policies or procedures, or the provision of auxiliary aids and services when determining eligibility for solid organ transplantation. Even with the provision of reasonable modifications or auxiliary aids and services, an individual may still be ineligible for transplant on grounds of medical unsuitability. Thus, the available remedies preserve the autonomous medical decision-making of the transplant physician while rectifying disability-based eligibility decisions.

Mandated individualized assessment

The Act contains a general prohibition against disability-based discrimination: "a covered entity may not, solely on the basis of a qualified individual's…disability deem such individual ineligible to receive an anatomical gift or transplant."[215] The Act's antidiscrimination mandate applies to the entire spectrum of transplantation services, which starts with a referral to a transplant center and concludes with

[207] *Id.* §§(3)(c), (3)(d)(3).
[208] Whitehead, *supra* note 18, at 491.
[209] H.R. Res. 8981, §(2)(7)(B).
[210] Frank, *supra* note 20, at 107.
[211] *See* Tran, *supra* note 17, at 637.
[212] Crossley, *supra* note 98, at 56; Frank, *supra* note 20, at 106; Nat'l Council on Disability, *supra* note 14, at 50.
[213] Nat'l Council on Disability, *supra* note 14, at 50.
[214] H.R. Res. 8981, §(4)(c).
[215] H.R. Res. 8981, §(4)(c).

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post-transplant treatment.[216] Although the Act is narrow in scope, its application to the entirety of the transplant evaluation process would help syphon out the negative biases associated with intellectual disability from the evidence-based selection criteria that should govern eligibility decisions. The anti-discrimination provisions prevent the utilization of selection criteria that deny eligibility for organ transplant based on an individual's membership to a class with a shared characteristic, namely I/DD.

The Act requires compliance with the affirmative obligations set forth in Titles II and III of the ADA.[217] A failure to perform an individualized assessment risks making an determination of eligibility based on the individual's membership in a group, and consequently, exclude a whole class of individuals from transplant on the basis of disability alone.[218] An individualized consideration of disability required by the ADA is of significance to the organ transplantation process because it would require a transplant team, or transplant physician, to perform an individualized evaluation of candidacy for organ transplant.[219] In *Abbott*, a dentist refused to perform a dental surgery on an HIV-positive female patient. The question for the Supreme Court was whether a "direct threat" of HIV transmission, under Title III of the ADA, should be viewed from the perspective of the physician refusing to perform the operation. The Court reasoned that the risk of transmission should be viewed from the perspective of the physician, but the physician's assessment must be based on objective evidence.

Similar to the Supreme Court's reasoning in *Bragdon v. Abbott*, eligibility for transplant should be evaluated from the perspective of the transplant team, and other physician stakeholders (e.g., surgeons).[220] However, the denial of transplant candidacy must be based on the objective and evidence-based results of an evaluation for eligibility, rather than on the unfavorable biases associated with intellectual disability.[221] Good-faith subjective beliefs about prognostic post-transplant clinical outcomes (e.g., post-transplant adherence) alone will not shield a transplant physician from civil liability, unless those beliefs are supported by objective evidence.[222] Given that some available evidence indicates that post-transplant outcomes for intellectually disabled individuals are similar to nondisabled organ transplant recipients, harmful prejudices will likely remain unjustified bases for a denial of transplant candidacy.[223]

"Medically significant"

Certain psychosocial factors may jeopardize the success of an organ transplant and are legitimate considerations that may be appropriate grounds for denial.[224] The consideration of psychosocial criteria becomes invidious when transplant teams use these criteria as mechanisms for covert determinations of social worth.[225] Disproportionate weight placed on psychosocial risk factors for intellectually disabled individuals results in a variance in the stringency of application of selection criteria between intellectually disabled and nondisabled individuals.[226] Burdening intellectually disabled individuals with higher eligibility thresholds is likely violative of the statutory prohibition on holding disabled individuals to a higher standard of anticipated benefits from solid organ transplantation.[227]

[216] *Id.* §(3)(a)(1)-(5).
[217] H.R. Res. 8981, §(3)(d)(2).
[218] Whitehead, *supra* note 18, at 491.
[219] Nat'l Council on Disability, *supra* note 14, at 47, 54 (noting that some transplant centers are not following federal law by failing to assess sthe impact of an individual's disability on her eligibility for solid organ transplant).
[220] Bragdon v. Abbott, 524 U.S. 624, 624 (1998).
[221] *Id.* at 648.
[222] *Id.* at 650.
[223] Ross, *supra* note 74, at 7.
[224] Frank, *supra* note 20, at 118-19.
[225] Richards, *supra* note 8, at 167-68; Hoffman, *supra* note 8, at 159-60.
[226] Frank, *supra* note 20, at 125; Olbrisch & Levenson, *supra* note 40, at 238-39. *See* Hoffman, *supra* note 8, at 152; *See also* Cmty. Ethics Comm., *supra* note 92, at 4-5.
[227] Emma Samelson-Jones et al., *supra* note 42, at 137; Richards, *supra* note 8, at 163-64.

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The Act permits the consideration of an I/DD as a contraindication if the disability contributes to clinical incompatibility for solid organ transplantation.[228] For example, some suggest that it may be medically reasonable to consider I/DD as a relative contraindication for solid organ transplant when genetic disorders increase the risk of malignant comorbidities or post-transplant medical complications (e.g., infections).[229] The "medically significant exception" narrows the scope of the transplant team's or transplant physician's discretion in eligibility decisions, which may mitigate concerns discussed above. Under the Act, selection committees and its transplant physicians could no longer deny eligibility on psychosocial grounds alone, but rather, the transplant physician would need to articulate medically relevant reasons that disqualify the individual from eligibility.[230]

The Act thus creates a shift in the default for intellectually disabled persons. As with nondisabled persons, an intellectually disabled individual who could medically benefit from an organ transplant is, by default, eligible for a transplant, unless the disability is medically significant to the provision of transplant-related services. If the intellectual disability does not have medical significance for measurable post-transplant outcomes (e.g., length of patient and graft survival), then the intellectual disability cannot be considered a contraindication to organ transplantation.[231]

Individuals whose cognitive or intellectual disabilities pose high risks for medical complications post-transplant may be legitimately denied transplant eligibility.[232] The exception strikes a balance between the unjustified regulation of the practice of transplant medicine and the physician's professional obligation to prevent the premature loss of a viable organ because of medical incompatibility or post-transplant nonadherence.[233]

HR 8981: foreseen drawbacks

New federal legislation that provides clear guidance for transplant centers and its transplant physicians would be a strong mechanism for eliminating disability-based discrimination within the organ transplant evaluation process. But the Act's potential impact on eliminating disability-based discrimination may be undermined by the same or similar pitfalls that stunt the effect of current antidiscrimination statutes.

Enactment-related difficulties

Enacting new legislation can be challenging.[234] Unlike the rapid surge of attention during the COVID-19 pandemic to the disability-based discrimination baked into multiple states' crisis standards of care plans, discriminatory transplant eligibility decisions have not enjoyed the same rise to national attention.[235] Congressional priorities would be the first hurdle that proponents of the Act will need to address. The Act's codification into federal law will be challenging if Congress fails to prioritize anti-discrimination legislation. Absent national focus on — and awareness of—disability-based eligibility practices and procedures, Congress is unlikely to demonstrate sufficient interest to prioritize the Act.[236] Proponents

[228]A question arises: to what degree does a disability need to be medically significant to the determination of eligibility in order to satisfy the exception. The degree of medical significance remains an open question for future litigation.

[229]Samelson-Jones et al., *supra* note 42, at 137.

[230]Richards, *supra* note 8, at 189-92.

[231]Wightman et al., *supra* note 83, at 3.

[232]*See, e.g.*, Tran, *supra* note 17, at 639.

[233]Frank, *supra* note 20, at 123, 134.

[234]*See* Richards, *supra* note 8, at 191.

[235]Ne'eman et al., *supra* note 167, at 852. These authors note that the rapid evolution of disability-based crisis standards of care plans rose from obscurity to prominence because of behind-the-scenes negotiations that involved advocacy mobilization and media attention to medical resource allocation. *Id.*

[236]*See* Frank, *supra* note 20, at 107.

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may need to consider more modest alternative legislative strategies that would achieve the same goal, namely, a congressional amendment to the ADA or the National Organ Transplant Act.[237]

Additionally, the Act's language, as written, may stir opposition from large professional organizations and societies (e.g., American Medical Association), which could argue that the Act would unfairly impede on the independent practice of transplantation medicine, specifically a transplant physician's clinical judgments.[238] As discussed above, the Act protects the integrity of a transplant physician's clinical determinations to the extent that those determinations are not discriminatory in nature. With recent media attention to crisis standards of care plans and disability-based discrimination, disability-rights activists and advocates significantly influenced public policy over the course of the COVID-19 pandemic.[239] These types of partnerships have the ability to shift the scope of social and political discussion surrounding disability-based transplant eligibility decisions from academic discourse to policy development.[240] Therefore, partnering with national intellectual disability organizations (e.g., American Association on Intellectual and Developmental Disabilities) and advocacy groups could help counter opposition and foster collaboration between competing constituents.

Creating national guidelines for the evaluation of transplant candidacy for intellectually disabled individuals could be well within the capacity of the United States Access Board, which is an independent federal agency that develops accessibility guidelines and standards for covered entities with relevant stakeholders, including transplant physicians and individuals with disabilities.[241] Access Board guidelines could serve as regulatory companions necessary to ensure compliance with the Act's affirmative obligations on transplant centers. The Access Board could offer recommended model guidelines for transplant centers to integrate into existing policies, procedures, and practices.

An additional advantage of utilizing the Access Board is that representation from key stakeholders in the drafting of transplant evaluation guidelines may reduce anticipated objections from professional medical organizations and disability-rights activists. The swift shift away from the categorically discriminatory language present in states' earlier Crisis Standards of Care plans resulted from negotiations between policy makers and disability-rights activists. The participation of disabled persons in the development of appropriate psychosocial evaluative criteria can help avoid errors in the application of psychosocial evaluations for transplant.[242]

The challenges accompanying national legislative framework

New federal legislation would clarify the relevance of anti-discrimination legislation to the organ transplantation process and serve as a national repudiation of discrimination on the basis of intellectual disability.[243] Self-imposed regulations on transplantation medicine result in differences in enforcement and stringency in implementation among transplant centers.[244] A national legislative framework would offer a uniform approach that protects individuals with I/DDs from insidious discrimination that denies access to organ transplantation.[245] The Act improves upon current federal legislation by creating a standard definition of discrimination within the context of the organ transplantation evaluation process.

But the proposed legislative solution mirrors state-level statutes whose framework is borrowed from a federal anti-discrimination framework, which has proven to be unenforceable in transplant eligibility decisions.[246] The Act alone is a piece-meal resolution that will present the same enforcement gaps in

[237]Richards, *supra* note 8, at 170.
[238]Frank, *supra* note 20, at 107; Richards, *supra* note 8, at 170.
[239]Ne'eman et al., *supra* note 167, at 851.
[240]*Id.* at 852.
[241]*About Us*, U.S. Access Board: Advancing Full Access and Inclusion for All, https://www.access-board.gov/about/ [https://perma.cc/J7GM-THED] (last visited Aug. 8, 2021).
[242]Guidry-Grimes et al., *supra* note 46, at 30.
[243]Frank, *supra* note 20, at 107-08.
[244]Tran, *supra* note 17, at 662.
[245]*Id.*
[246]*Id.* at 660-62.

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existing state and federal legislation. It is advisable that selection committees, and its transplant physicians, retain broad discretion in eligibility decisions to the extent that they do not exclude intellectually disabled individuals from organ transplant eligibility on the basis of disability alone. Given the potential for covert discrimination under the guise of neutral selection criteria, clarifying the legality (or illegality) of considering evaluative psychosocial criteria in eligibility decisions would help ensure rejections are based on "medically significant" grounds.[247] For example, in Section 3(b)(2) (entitled "Clarification") a later iteration of the Act could include language that explicitly outlaws denial of eligibility on the basis of psychosocial criteria alone unless the physician can articulate medically relevant reasons for the denial.[248] On the other hand, the Act could clarify that it bars rejection of eligibility if the potential candidate can demonstrate support systems or services that mitigate risk variables that negatively impact post-transplant outcomes.[249] This challenge underscores the need for a robust systematic initiative that includes a regulatory companion to the Act and other existing federal statutes.[250]

Enforcement challenges

Lack of awareness about the Act and its affirmative obligations may stymie its enforceability.[251] An intellectually disabled individual or her legally authorized representative may not be aware that she has been subject to discrimination or, if she is aware of discriminatory motives at work, may not have knowledge of available remedies under the Act. Passage of the Act will garner attention from health care facilities with transplant programs, but it does not guarantee that disabled individuals have knowledge of the Act. Similar to enforcement issues of other federal statutes, the individual who has been subject to discrimination will need to consider whether to pursue a claim in the face of prognostic uncertainty and opportunities to seek evaluation elsewhere. It would be advantageous for proponents of the Act to partner with a national coalition of disability organizations to develop educational strategies to increase public knowledge of available remedies. An amended version of the statute could include a provision that requires transplant centers to provide a copy of policies and procedures addressing its transplant-related services to those seeking an evaluation.

Although the Act clarifies the relevance of existing federal statutes to the organ transplantation process, similar enforcement downfalls will likely frustrate its intended goals. Theoretically, litigation promotes enforcement, and increased enforcement motivates increased institutional compliance.[252] A private right of action under Title III of the ADA does not allow plaintiffs to recover damages.[253] Like the ADA, the Act's available remedies are limited to equitable and injunctive relief, and therefore, do not permit a damages award.[254] But the Act's remedies are significantly narrower than Title III's available remedies.[255] Title III permits courts to assess civil penalties up to $50,000 for the first violation and $100,000 for subsequent violations and award damages to the plaintiffs at the Attorney General's request.[256]

[247]H.R. Res. 8981, 116th Cong. §(3)(b)(1). Consideration of disability does not violate the statute when the transplant physician determines the disability is "medically significant to the provision of the anatomical gift." *Id.*

[248]*See id.* §(3)(b)(2).

[249]*See* Richards, *supra* note 8, at 171.

[250]For example, at the direction of HHS, UNOS could create uniform selection criteria. Additionally, regulatory guidelines could explain how to use psychosocial criteria appropriately so that eligibility decisions are not based on social worth determinations.

[251]Nat'l Council on Disability, *supra* note 10, at 50.

[252]*See id.* at 13.

[253]Carri Becker, *Private Enforcement of the Americans With Disabilities Act via Serial Litigation: Abusive or Commendable?,* 17 Hatsings Women's L. J. 93, 97 (2006).

[254]H.R. Res. 8981, 116th Cong. §(4)(b)(1)-(3).

[255]*Compare id.* (stating that no civil penalties are available for violation of the Act), *with* Kristi Bleyer, *ADA: Enforcement Mechanisms*, 15 Mental and Physical Disability L. 347, 349 (1992) (stating that the Title III remedies may include civil penalties up to $100,000 for repeated violations).

[256]Bleyer *supra* note 262, at 349.

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Similar to its state counterparts,[257] the Act does not contain strong enforcement mechanisms, like civil penalties, that would incentivize compliance with the Act and other statutory requirements within federal legislation.[258] In its current version, the Act's limited remedies are not likely to yield the significant litigation exposure that would encourage hospitals with transplant programs to create preventative robust risk management strategies and compliance programs aimed at eliminating discrimination in its eligibility decisions.[259] Absent expansive efforts to eliminate discrimination in the transplant evaluation process, case-by-case enforcement provides for individualized relief, but does not lend itself to standardized evaluation criteria for transplant centers.[260]

Recommendations

Much has been written about federal regulatory and judicial solutions that could better address disability-based discrimination against intellectually disabled individuals within the transplant evaluation process.[261] Less has been written about proactive and concrete solutions that could prevent discrimination when an intellectually disabled individual requests an organ transplant evaluation at a transplant center. The following recommendations aim to reform current evaluation protocols by removing accessibility barriers for the intellectually disabled community.

Some may argue that the proposed recommendations would impose premature and unwarranted economic and personnel burdens on transplant centers because the bill is not yet a federal law that imposes any affirmative obligations. While a legitimate argument, current federal antidiscrimination law already imposes an affirmative obligation on transplant centers to conduct an individualized assessment of a potential candidate with an I/DD in the same or similar manner as an individual without an I/DD. Therefore, the recommendations herein serve another more immediate purpose: to ensure compliance with the affirmative obligations imposed by already-existing federal antidiscrimination statutes. It might seem that the recommendations would not have a significant impact on eliminating discrimination unless transplant centers voluntary self-regulate against discrimination, especially when the medical profession enjoys a significant degree of self-regulation.[262] Compliance with statutory requirements of Title II and Title III and Section 504 reduces exposure to civil liability. Avoiding civil liability would likely incentivize the adoption of self-regulating anti-discriminatory eligibility practices.

Part IV examines potential solutions at two levels: (1) professional organizations and (2) local transplant centers. Section A of Part IV proposes that professional organizations, like transplantation societies, could provide more robust guidance for the evaluation of transplant candidacy for intellectually disabled persons. Section B offers several concrete courses of action that transplant centers could take to ensure compliance with present and potential future antidiscrimination mandates.

Transplant societies: professional guidance

Position statements alone cannot achieve the intended goal of antidiscrimination legislation: to minimize—if not, wholly prevent—bias. Some transplant societies have published position statements that disavow discrimination based on disability.[263] For example, the American Society of Transplant

[257]Frank, *supra* note 20, at 103-04.
[258]H.R. Res. 8981, §(4)(b)(1)-(3).
[259]Frank, *supra* note 20, at 108.
[260]*See* Richards, *supra* note 8, at 171.
[261]Frank, *supra* note 20, at 108; Nat'l Council on Disability, *supra* note 14, at 65-70; Tran, *supra* note 17, at 655-56; Richards, *supra* note 8, at 179-80.
[262]Ne'eman et al., *supra* note 167, at 855.
[263]Richards, *supra* note 8, at 192-93;

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Surgeons "supports efforts to identify and eliminate any Transplant Center processes or practices that allow discrimination based on….disability."[264] While position statements provide valuable governing ethical principles for the practice of transplantation medicine, these types of general statements alone do not incentivize compliance from transplant centers or transplant physicians. Position statements fail to give practical guidance about how to avoid disability-based decision making when evaluating an individual with I/DD for organ transplant.[265]

Instead, recommendations should focus on developing equitable processes for the evaluation of an intellectually disabled person for organ transplantation. For example, a work group of kidney transplant physicians published clinical practice guidelines intended to assist physicians and other allied health care professionals in the management and evaluation of potential kidney transplant candidates.[266] The guideline recommends that individuals with cognitive or intellectual deficits should not be categorically excluded from a kidney transplant evaluation[267] and address issues related to neurocognitive assessments in potential transplant candidates.[268] Transplant centers could avoid disability-based discrimination by adopting and implementing these types of clinical guidelines because the working assumption is the guidelines were developed for the purpose of giving individuals with I/DDs equitable access to organ transplantation.

Professional consensus about the appropriate evaluative criteria of intellectually disabled persons for organ transplant is an essential prerequisite to developing evidence-based model guidelines for transplant centers.[269] As Chen et al—an interdisciplinary group of physicians, living donors, living donor advocates, social workers, and ethicists—suggest, achieving professional consensus requires increased empirical research across the organ transplantation process and collection of surveillance data of referral and listing decisions for intellectually disabled persons.[270] As key components to the development of professional guidelines, legal and regulatory frameworks would ensure that any proposed recommendations are compliant with present and future antidiscrimination statutes.

Professional guidance informed by the data, law, and ethics would better identify psychosocial variables that could be medically significant to preclude eligibility. Guidelines could include instructions on how to evaluate medical and psychosocial risk factors separately. Transplant teams could categorize potential candidates along a multi-axis risk classification spectrum that accounts for both types of risk factors (Figure 1). The medical risk classification (x-axis) is based on the presence of other significant comorbidities or diagnoses that make an individual low-risk, moderate-risk, or high-risk for medical unsuitability for organ transplant. A secondary classification of low, moderate, or high psychosocial risk (y-axis) is dependent upon the presence of standardized psychosocial risk factors that are medically significant to transplant eligibility; whether psychosocial risk factors are medically significant to jeopardize post-transplant success is determinative of an individual's psychosocial risk classification. As shown in Figure 1, the two classifications combined would result in a cumulative risk classification.

Others have suggested categorizing potential candidates as high-risk, moderate-risk, or low-risk for organ transplantation along a single-axis risk classification spectrum.[271] A single classification still risks the possibility for a transplant physician to assign disproportionate significance to psychosocial factors,

[264]*Statement of Principles for Organ Donation and Transplantation*, Position Statements, American Society of Transplant Surgeons (April 12, 2021), https://asts.org/about-asts/position-statements#.YO9HqRNKiWA [https://perma.cc/55DT-WE85].

[265]Richards, *supra* note 8, at 171.

[266]Kidney Disease: Improving Global Outcomes (KDIGO) Kidney Transplant Candidate Work Group, *KDIGO Clinical Practice Guideline on the Evaluation and Management of Candidates for Kidney Transplantation*, 104 Transplantation S1-S103 (2020).

[267]*Id.* at S73.

[268]*Id.* at S36.

[269]Chen et al., *supra* note 14, at 2014.

[270]*Id.*

[271]Tran, *supra* note 17, at 663-64; *see* Frank, *supra* note 20, at 124-25.

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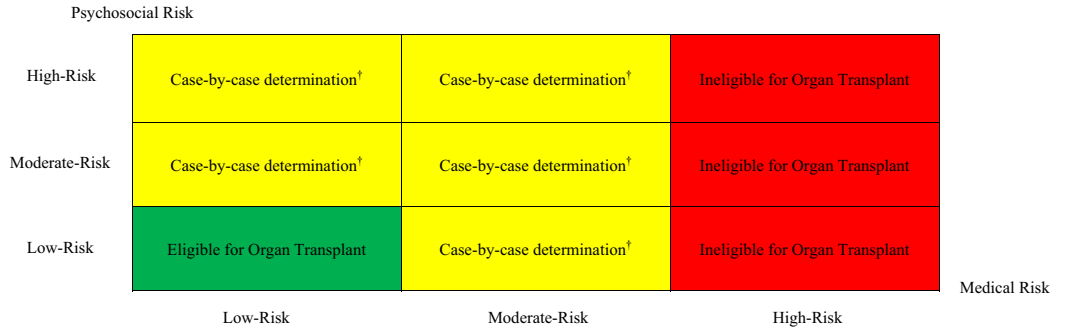

Figure 1. Figure 1 demonstrates how independent assessments of medical risk and psychosocial risk results in a cumulative risk assessment for transplant eligibility.

which promotes covert disability-based discrimination. A two-classification system helps the physician determine eligibility based on the degree to which psychosocial risk variables are medically relevant to transplant candidacy.

Transplant center-level solutions

Revising transplant center policies

Transplant centers could review and revise current institutional policies to ensure basic compliance with Titles II and III of the ADA and Section 504. For example, the language of the policy could include a requirement that transplant centers conduct individualized evaluations of intellectually disabled persons' candidacies, and based on the outcome of the evaluations, provide reasonable accommodations that support candidacy for solid organ transplantation.[272] Recognizing the lack of federal regulation defining "reasonable accommodations" within the context of the initial evaluation stages, transplant centers could consult with the OCR or state-based intellectual disability organizations to identify accommodations that strengthen an intellectually disabled individual's candidacy.

Transparent decision-making

Transplant teams and transplant physicians have wide discretion in the creation and application of their selection criteria, which results in idiosyncratic eligibility decisions.[273] Current practice lends itself to covert disability-based discrimination that is difficult for plaintiffs to prove.[274] To disincentivize this type of discrimination, institutional policies and procedures could require transplant physicians provide a signed written explanation of their decision to deny transplant eligibility to the patient (or the patient's legal representative) and include the statement within the patient's medical record.[275] A written statement detailing the rationale for a denial of eligibility would be an attestation that the decision is not based solely on the individual's intellectual disability to the extent that it is not medically significant to the clinical outcomes of the transplant.[276] Components of the statement could include (1) a description of the individualized evaluation provided, (2) medical and psychosocial

[272]*See generally* Richards, *supra* note 8.
[273]Richards, *supra* note 8, at 158.
[274]Crossley, *supra* note 98, at 56; Frank, *supra* note 20, at 108; Nat'l Council on Disability, *supra* note 14, at 50.
[275]Frank, *supra* note 20, at 133-34; Tran, *supra* note 17, at 642.
[276]Frank, *supra* note 20, at 133-34.

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barriers that precluded transplant, (4) reasonable modifications provided to support the individual's candidacy, (4) language disavowing that the consideration of the intellectual disability alone was determinative of eligibility, and (5) circumstances under which, if present, the transplant center would consider revaluation of the individual. Increasing transparency by written communication with the potential candidate increases a transplant physician's accountability to make evidence-based clinical decisions regarding transplant eligibility for intellectually disabled individuals and avoid determinations of social worth.

Standardized psychosocial evaluation tools

The use of I/DDs as a contraindication, whether absolute or relative, remains unsettled within the practice of transplantation medicine.[277] For example, calls for standardized psychosocial criteria identify mental status as an appropriate domain for evaluation.[278] Mental status itself may be uncontroversial and is likely a medically relevant criterion for transplant candidacy; however, mental status by nature contemplates deficits in an individual's cognitive function.[279] As a psychosocial evaluation criterion, cognitive function could be a placeholder for discriminatory determinations of social worth because unfounded misconceptions about intellectually disabled individuals' functional capabilities negatively influence eligibility decisions.[280]

The development of Crisis Standards of Care during the COVID-19 pandemic made clear that objective evaluation tools can exacerbate existing inequities between (intellectually) disabled and nondisabled persons when they do not account for necessary reasonable modifications specific to the disabled community.[281] Accounting for impairments in cognitive function coupled with the position that higher cognitive functioning could increase post-transplant adherence and participation in complex treatment regimens risks systematically poorer psychosocial evaluation results for intellectually disabled individuals.[282]

Other widely accepted psychosocial criteria (e.g., independence) pose the same types of risks.[283] For example, some disabilities require continual (bedside) support from the disabled individual's caregivers.[284] Psychosocial evaluation tools that do not account for the need for caregiver support will result in a poorer psychosocial evaluation outcome than a nondisabled person. Federal antidiscrimination laws, as discussed above, require reasonable modifications to policies, practices and procedures to a service or program unless it fundamentally alters the nature of the program.[285] Incorporation of adaptive functioning into the psychosocial evaluations could hardly be considered a fundamental alteration when, as others have noted, the modifications enhance the purpose of the psychosocial evaluation: to identify psychosocial factors that impact post-transplant success. Thus, if psychosocial evaluations, as risk stratification tools, do not account for reasonable modifications and the necessary auxiliary aids and services that individuals with I/DDs require, then transplant centers risk the unfair—and illegal—treatment of a whole class of individuals.

Furthermore, an emerging consensus suggests that cognitive function is an inadequate measure of an individual's intellectual disability.[286] The social model of disability focuses on the interaction between

[277]Chen et al., *supra* note 14, at 2010; Nat'l Council on Disability, *supra* note 14, at 30-31.
[278]Bui et al, *supra* note 33, at 9.
[279]*Id.* at 10.
[280]Statter et al., *supra* note 29, at 3-4.
[281]Guidry-Grimes et al., *supra* note 46, at 28; Ne'eman et al., *supra* note 167, at 841.
[282]For a discussion of why cognitive function is an appropriate consideration in this context, *see* Bui et al, *supra* note 33, at 2.
[283]Richards, *supra* note 8, at 167-68.
[284]*See id.*
[285]*See, e.g.*, Nat'l Council on Disability, *supra* note 14, at 47.
[286]Femke Jonker et al., *The Adaptive Ability Performance Test (ADAPT): A New Instrument for Measuring Adaptive Skills in People with Intellectual Disabilities and Borderline Intellectual Functioning*, 0 J. of Applied Res. in Intell. Disabilities 1156, 1156 (2021); Statter et al., *supra* note 29, at 2.

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social attitudes toward disability, the environment, and pathology.[287] This model suggests that disability is a social construct that results from environmental conditions that disadvantage a group of people.[288] Consistent with this model of disability, an intellectually disabled individual's level of functioning is more accurately measured by the practical or "day-to-day" skills (e.g., communication) necessary to interact with her environment.[289] Adaptive behavior is the "social and practical skills that enable people to function in their everyday life."[290] Incorporating adaptive behavior evaluations into eligibility assessments of an intellectually disabled individuals' candidacy provides a more expansive view of the intellectually disabled person's daily functioning with and without auxiliary aids and services. Within the context of psychosocial evaluations, the degree of cognitive function as measured by an adaptive functioning evaluation would help inform clinical determinations of whether an intellectual disability, or disability-related psychosocial risk variables, are medically significant factors that should preclude organ transplantation.

Integration of adaptive behavior assessments into candidacy evaluations presents logistical challenges. Intellectually disabled individuals often require additional support from a multidisciplinary transplant team to coordinate complex psychosocial care plans.[291] Hiring additional social workers or transplant coordinators with expertise in conducting adaptive behavior evaluations may be cost prohibitive.[292] Further, adopting these types of evaluations as a component of transplant protocols will require education and training for transplant social workers and coordinators whose time is limited.[293] A workable alternative may be to task another member of the multidisciplinary team, like a transplant psychiatrist, to conduct the adaptive behavior evaluation. Hospital and transplant center operations administrators will need to generate creative solutions that ensure the incorporation of adaptive behavior instruments into transplant center evaluation procedures for individuals with I/DDs.

Conclusion

Disability-based discrimination is pervasive. Within the context of limited viable organs, transplant teams wield significant discretionary authority in eligibility decisions. Determinations of transplant candidacy are an exercise in the allocation of scarce medical resources that unfortunately require the prioritization of one individual over another. The decision to accept or deny an individual as a candidate for solid organ transplantation is intended to achieve successful post-transplant clinical outcomes. Broad medical discretion is a necessary component to prevent the premature loss of a viable organ.

But transplant teams must be careful not to permit negative biases about intellectually disabled individuals influence the development of selection criteria. Transplant and other relevant stakeholder physicians must exercise caution in the application of selection criteria to prevent the exclusion of a total class of individuals. Without question, there are some circumstances in which the degree and type of an I/DD is so medically significant to the provision of an organ transplant that the I/DD will preclude organ transplant eligibility. However, a denial of eligibility based on intellectual disability alone warrants

[287]Dorfman, *supra* note 28, at 200; Emens, *supra* note 16, at 1401; Sagit Mor, *Disability and the Persistence of Poverty: Reconstructing Disability Allowances*, 6 NW J. L. & Soc. Pol'y, 178, 180 (2011).

[288]Dorfman, *supra* note 28, at 200; Emens, *supra* note 16, at 1401; Hoffman, *supra* note 8, at 164; Statter et al., *supra* note 29, at 4.

[289]Statter et al., supra note 29, at 2.

[290]Guilia Baldoni et al., *Influence of Adaptive Behavior on the Quality of Life of Adults with Intellectual and Development Disabilities*, 33 J. of Applied Res. in Intell. Disabilities 584, 586 (2020).

[291]Chen et al., *supra* note 14, at 2013-14.

[292]Although outside the scope of this Note, Chet et al. argue that current risk adjustment and reimbursement schemes disincentivize transplant centers from accepting intellectually disabled individuals because of "super additive" costs associated with disabled patients. *Id.* at 2014.

[293]*Id.* at 2013.

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skepticism when available data indicates that individuals with I/DDs have outcomes similar to non-disabled individuals.

Current federal and state statutory protections may not be sufficient to counter discriminatory eligibility decisions successfully. With the ability to mask discrimination behind facially neutral selection criteria, showing discrimination is difficult. The lack of federal guidelines creates ambiguity about the relevance and application of federal anti-discrimination legislation. The inability to enforce federal statutes consistently stunts the impact of discrimination within the context of organ transplantation. Improvements in the current organ transplant allocation system are needed. New proposed federal legislation offers some overdue improvements to current legislation, but as written may be susceptible to the same disadvantages that plague federal and state statutes.

The fate of the bill is uncertain. In the face of the unpredictability of the legislative process, more immediate action items could bring transplant centers into compliance with existing statutory mandates. Transplantation societies should collaborate to develop official recommendations addressing the appropriate evaluation of intellectual disabled individuals. Local transplant centers could take concrete steps to offset disability-based eligibility decisions that are violative of federal law. While systematic multi-pronged initiatives are needed to eliminate disability-based discrimination completely, practical solutions to the latent issues posed by the current evaluation process are necessary intermediate steps to ensuring equitable access to organ transplantation and its related services for intellectually disabled individuals now and in the future.

Adam Peña, MA, is a Clinical Ethicist and Senior Project Manager for the Biomedical Ethics Program within the Houston Methodist System. He also has a faculty appointment in the Center for Medical Ethics and Health Policy at Baylor College of Medicine. He received his Bachelor of Arts in Philosophy and Letters from the University of Dallas, a Master of Arts in Theology from University of St. Thomas, and a Master of Arts in Bioethics from Case Western Reserve University. He is currently pursuing his JD/LLM at the University of Houston Law Center.

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