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## **ORGAN TRANSPLANTATION ELIGIBILITY: DISCRIMINATION ON THE BASIS OF COGNITIVE DISABILITY**

*Tien-Kha Tran\**

*Congress passed the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 in response to the extensive history of discrimination Americans with disabilities have faced. These federal statutes provide that no individual is to be precluded from enjoying the programs provided by certain entities solely on the basis of their disability. However, this is difficult in regards to organ transplantation and individuals with cognitive disabilities. The issue lies where a physician is faced with the difficult decision in pursuing their moral and ethical obligations to preserve life while determining whether a specific cognitive disability is a contraindication for organ transplantation. This Note advocates for federally implemented guidelines, supplementing current federal antidiscrimination statutes, which would be more stringent on healthcare providers and provide clarity to physicians to prevent discrimination in determining whether an individual with a cognitive disability should receive an organ transplant. This Note provides the background of the applicable federal antidiscrimination statutes and judicial interpretation of the applicable statutes as well as the difficulties in procuring an organ transplant and the risks subsequent to an organ transplant procedure. Additionally, this Note discusses public policies and how*

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*some states have taken steps to deter discrimination. This Note will also provide an analysis of physician discretion in evaluating organ transplant eligibility and how absolute discretion presents the opportunity for discrimination. Lastly, this Note provides solutions, including judicial intervention and policy reform implementing a spectrum of risk classification, and mandatory disclosure of the reasons for transplantation refusal.*

## INTRODUCTION

The moment Maverick Higgs took his first breath on September 29, 2012, he was in dire need of a heart transplant.<sup>1</sup> Maverick was born with a heart condition called Hypoplastic Left Heart Syndrome (“HLHS”), “a birth defect that affects normal blood flow through the heart.”<sup>2</sup> During the baby’s development in pregnancy, the left side of the baby’s heart does not form properly.<sup>3</sup> After two surgical interventions, Maverick’s New York-Presbyterian medical team determined that he required a heart transplant.<sup>4</sup> At first the hospital’s transplant program deemed Maverick “an eligible transplant candidate.”<sup>5</sup> Unfortunately, two days later, doctors diagnosed Maverick with Coffin-Siris syndrome (“CSS”).<sup>6</sup> CSS is a cognitive disability and is also a rare genetic defect.<sup>7</sup> Due to his diagnosis, the doctors deemed Maverick ineligible for a new heart, informing his parents that he would have “a high risk for tumors and

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<sup>1</sup> Elizabeth Cohen, *Disabled Baby Denied Heart Transplant*, CNN (Nov. 30, 2013), <http://www.cnn.com/2013/11/30/health/disabled-transplants>.

<sup>2</sup> *Id.*; *Congenital Heart Defects (CHDs): Facts About Hypoplastic Left Heart Syndrome*, CTRS. FOR DISEASE CONTROL & PREVENTION (June 17, 2014), <http://www.cdc.gov/ncbddd/heartdefects/hlhs.html>.

<sup>3</sup> *Id.* When infants are born with HLHS, surgery conducted to treat HLHS is done in three stages. *Id.* However, these surgeries do not cure the infant. *Id.* Infants born with HLHS will require regular appointments with a cardiologist and life-long medication. *Id.* Moreover, if surgery weakens the infant’s heart beyond repair, a heart transplant may be needed. *Id.*

<sup>4</sup> *See* Cohen, *supra* note 1.

<sup>5</sup> *Id.*

<sup>6</sup> *Id.*

<sup>7</sup> *See Coffin Siris Syndrome*, NAT’L ORG. FOR RARE DISORDERS, <https://rarediseases.org/rare-diseases/coffin-siris-syndrome/> (last visited Mar. 7, 2016).

infections . . . . [Therefore,] a heart transplant would be too risky.”<sup>8</sup> Maverick’s story illustrates a problem that is common for those with cognitive disabilities seeking a life-saving organ transplant.

Determined to save her son, Maverick’s mother reviewed the findings of various medical studies of CSS.<sup>9</sup> The studies<sup>10</sup> contained no evidence that CSS patients had compromised immune systems.<sup>11</sup> She sought and received confirmation by e-mailing her inquiries to one of the researchers.<sup>12</sup> Despite her findings, Maverick’s doctors maintained that Maverick was ineligible for a transplant,<sup>13</sup> insisting that a transplant could put Maverick at a higher risk for tumors and infections.<sup>14</sup> Thereafter, Maverick’s father filed a complaint with the U.S. Department of Health and Human Services, alleging the hospital discriminated against Maverick “based on his disability,” thereby denying him a potentially life-saving procedure.<sup>15</sup>

Maverick’s need for a heart and the doctors’ denial raises the issue of whether precluding individuals with cognitive disabilities from receiving organ transplantation is pure discrimination and therefore a violation of Section 504 of the Rehabilitation Act of 1973

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<sup>8</sup> Cohen, *supra* note 1.

<sup>9</sup> *Id.*

<sup>10</sup> Maverick’s medical team provided his parents with information on CSS, which included a study by Dr. Gijs Santen. *Id.* Maverick’s mother subsequently contacted Dr. Santen to confirm whether children diagnosed with CSS have compromised immune systems. *Id.* Dr. Santen confirmed that children with CSS have “no objective problem with the immune system.” *Id.*

<sup>11</sup> *Id.* The medical team’s concern for Maverick being at an increased risk of tumors and infections was due to their belief that children with CSS have compromised immune systems. *See id.* In addition to a weak immune system, the risk “would be greatly magnified combined with the immunosuppression involved in transplantation.” *Id.*

<sup>12</sup> *Id.*

<sup>13</sup> Maverick’s parents were given contradicting reasons for denying him access to the transplant waitlist. *Id.* On May 6, 2013, two of Maverick’s doctors told his parents that “the doctors in Philadelphia had refused to give him a new heart for the same reason: that his Coffin-Siris syndrome meant he had a suppressed immune system.” *Id.* However, when Maverick’s mother inquired further, the Philadelphia doctor told her “Maverick’s genetic problems played very little role in their decision making.” *Id.*

<sup>14</sup> *Id.*

<sup>15</sup> *Id.*

and Title II of the American Disabilities Act of 1990.<sup>16</sup> This Note argues that federally funded organ transplant centers should implement stricter guidelines to prevent discrimination in determining whether an individual with a cognitive disability should receive an organ transplant, with the inquiry focusing on the best interest of the individual seeking transplantation. Furthermore, doctors should only have discretion to prevent transplants in situations where medical research confirms that a type of cognitive disability actually entails a higher risk of transplantation failure. This Note does not argue that discriminatory intent animates every determination by a physician that a disabled person is not eligible for an organ transplant. Rather, this Note argues that given the vast discretion afforded to physicians and the potential for discriminatory intent, increased oversight and heightened accountability are necessary to ensure eligibility determinations are made based solely on sound medical knowledge.

Part I of this Note discusses the background of the applicable federal antidiscrimination statutes and judicial interpretation of the applicable statutes. Part II discusses the difficulties in procuring an organ transplant, how the National Organ Transplant Act addresses the difficulties of organ procurement, the national waitlist for organ transplantation, and the risks subsequent to an organ transplant procedure. Part III of this Note discusses public policies—already adopted in a few states—and how they lend themselves to the solution proposed. Part IV of this Note will provide an analysis of physician discretion in evaluating organ transplant eligibility and how absolute discretion presents the opportunity for discrimination. Lastly, Part V of this Note provides solutions, including judicial intervention and policy reform implementing a spectrum of risk

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<sup>16</sup> See 29 U.S.C. § 794 (2012); see also 42 U.S.C. §§ 12101–12165 (2011). According to the Autistic Self Advocacy Network (“ASAN”), “[p]eople with disabilities may face discrimination when seeking potentially lifesaving organ transplants. In such cases, discrimination often happens at the point where [an individual] is referred for evaluation by a transplant center before [that individual is] ever placed on the official transplant waiting list.” *ASAN Joined by Coalition Supporting MD Anti-Organ Transplant Discrimination Bill*, ASAN: AUTISTIC SELF ADVOCACY NETWORK (Mar. 17, 2015), <http://autisticadvocacy.org/2015/03/asan-joined-by-coalition-supporting-md-anti-organ-transplant-discrimination-bill/> [hereinafter *ASAN Antidiscrimination Bill*].

classification, and mandatory disclosure of the reasons for transplantation refusal.

## I. BACKGROUND: FEDERAL STATUTES AND JUDICIAL INTERPRETATION

### A. *Applicable Federal Statutes*

Federally funded and public entities fall within the requirements of Section 504 of the Rehabilitation Act of 1973 (“Section 504”) and Title II of the American Disabilities Act of 1990 (“Title II”). Both statutes protect individuals from discrimination by healthcare providers.<sup>17</sup> Section 504 specifically applies to entities that receive any amount or form of financial assistance from any of the federal departments or agencies.<sup>18</sup> This nondiscrimination statute protects individuals from discrimination based on disability by prohibiting these federally funded entities “from excluding or denying individuals with disabilities an equal opportunity to receive program benefits and services.”<sup>19</sup> Section 504 protects “physical or mental impairment[s] [which] substantially limit[] one or more major life activities[;] . . . [an] example[] of impairment[] [includes] . . . *mental illness*.”<sup>20</sup>

Title II protects the same types of “qualified individuals with disabilities”<sup>21</sup> but is distinguishable from Section 504 insofar as it applies to all public entities, regardless of whether the entity

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<sup>17</sup> See *Discrimination on the Basis of Disability*, U.S. DEP’T HEALTH & HUM. SERVS., <http://www.hhs.gov/ocr/civilrights/understanding/disability/> (last visited Mar. 7, 2016).

<sup>18</sup> *Fact Sheet: Your Rights Under Section 504 of the Rehabilitation Act*, U.S. DEP’T HEALTH AND HUM. SERVS., <http://www.hhs.gov/sites/default/files/ocr/civilrights/resources/factsheets/504.pdf> (last visited Mar. 7, 2016) [hereinafter *Fact Sheet Section 504*].

<sup>19</sup> *Id.*

<sup>20</sup> *Id.* (emphasis added).

<sup>21</sup> See *Fact Sheet: Your Rights Under the Americans with Disabilities Act*, U.S. DEP’T HEALTH AND HUM. SERVS., <http://www.hhs.gov/sites/default/files/ocr/civilrights/resources/factsheets/ada.pdf> (last visited Mar. 7, 2016) [hereinafter *Fact Sheet ADA*].

receives federal funding.<sup>22</sup> Title II defines “[a]n individual with a disability [a]s a person who has a physical or mental impairment that substantially limits major life activities; has a record of such an impairment; or is regarded as having such an impairment.”<sup>23</sup> This statute protects individuals from discrimination by public entities to provide them with the services and programs that the entity specializes in. For example, healthcare providers like hospitals cannot refuse care or deny participation in an organ transplantation program to an individual solely on the basis of their physical or mental disability.<sup>24</sup>

Violations of either of these statutes, based upon compliance reviews by the U.S. Department of Health and Human Services’ Office for Civil Rights (“OCR”), may result in consequences, such as decreased funding or sanctions.<sup>25</sup> In *Maverick’s* case, New York-Presbyterian Hospital is subject to Section 504 because it is federally funded.<sup>26</sup> While New York-Presbyterian Hospital may be a private entity, thus making Title II inapplicable, Section 504 has been interpreted consistently with Title II.<sup>27</sup>

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<sup>22</sup> *Disability Rights Section: Title II Highlights*, U.S. DEP’T JUST., <http://www.ada.gov/t2hlt95.htm> (last visited Mar. 7, 2016).

<sup>23</sup> *Fact Sheet ADA*, *supra* note 21.

<sup>24</sup> *See id.*

<sup>25</sup> *See Resolution Agreements*, U.S. DEP’T HEALTH & HUM. SERVS., <http://www.hhs.gov/hipaa/for-professionals/compliance-enforcement/agreements/index.html> (last visited Mar. 7, 2016) (noting that when HHS has not been able to “reach a satisfactory resolution through the covered entity’s demonstrated compliance or corrective action through other informal means, . . . civil money penalties (CMPs) may be imposed for noncompliance against a covered entity”).

<sup>26</sup> *Facts and Financials*, NEW YORK-PRESBYTERIAN, <http://nyp.org/about/facts-statistics.html> (last visited Mar. 7, 2016). The figures provided on New York-Presbyterian Hospital’s website indicate the types of funding it receives or types of payments that patients use for healthcare. *See id.* The fact that the hospital receives funds from both Medicaid and Medicare indicates that they receive some sort of federal assistance. *See id.*

<sup>27</sup> *See State and Local Governments (Title II)*, ADA.GOV, [http://www.ada.gov/ada\\_title\\_II.htm](http://www.ada.gov/ada_title_II.htm) (last visited Mar. 7, 2016); *see also ADA Regulation for Title II*, U.S. DEP’T JUST., <http://www.ada.gov/reg2.htm> (last visited Mar. 7, 2016) (“Because title II of the ADA essentially extends the nondiscrimination mandate of section 504 to those State and local governments

The decision as to whether the ADA or the Rehabilitation Act governs a certain circumstance depends on the determination of whether the ADA is limited to entities that receive federal funding. In *Coleman v. Zatechka*, the U.S. District Court for the District of Nebraska expanded the applicability of the ADA to all public entities after the University of Nebraska denied a paralyzed student a request to be assigned a roommate in campus housing.<sup>28</sup> The university never placed the student in the pool of students that were to be randomly assigned to a roommate because of her disability which required a personal attendant.<sup>29</sup> The court found that “the ADA is not limited to programs receiving federal funding, but rather applies to *all* public entities,”<sup>30</sup> indicating that no individual should be discriminated on the basis of their disability while trying to participate in programs provided by the entity.<sup>31</sup> The court further defined “[t]he term ‘public entity’ [to] include[] States and any department, agency or other instrumentality of a State.”<sup>32</sup> In *Coleman*, the university’s policy to exclude disabled students from the equal opportunity to participate in the roommate assignment program was a violation of the protections afforded by the ADA.<sup>33</sup> Similarly, in *Armstrong v. Wilson*,<sup>34</sup> the U.S. District Court for the Northern District of California found that the ADA expanded Section 504 to include *any* public entity, rather than just public entities receiving federal funding.<sup>35</sup> In *Kinney v. Yerusalim*, the U.S. District Court for the Eastern District of Pennsylvania broadly interpreted the terms and requirements of these statutes to protect a wider variety of individuals with disabilities, rather than just physical disabilities.<sup>36</sup>

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that do not receive Federal financial assistance, this rule hews closely to the provisions of existing section 504 regulations.”).

<sup>28</sup> *Coleman v. Zatechka*, 824 F. Supp. 1360, 1366–67 (D. Neb. 1993).

<sup>29</sup> *Id.* at 1362, 1366.

<sup>30</sup> *Id.* at 1367.

<sup>31</sup> See 42 U.S.C. §§ 12131–12165 (2012).

<sup>32</sup> *Coleman*, 824 F. Supp. at 1367.

<sup>33</sup> *Id.* at 1372–73.

<sup>34</sup> *Armstrong v. Wilson*, 942 F. Supp. 1252 (N.D. Cal. 1996).

<sup>35</sup> *Id.* at 1258–59.

<sup>36</sup> See *Kinney v. Yerusalim*, 812 F. Supp. 547 (E.D. Pa. 1993).



As courts have repeatedly found, federally funded and public entities are bound by both Section 504 and Title II. These entities are thus prohibited from refusing or denying participation in any programs or providing healthcare to individuals with either physical or mental disabilities on the sole basis of their disability.<sup>37</sup> If the entity employs any eligibility standards that result in discriminatory effects, the standards may be subject to a compliance review conducted by the U.S. Department of Health and Human Services.<sup>38</sup> These entities must provide an environment that is least restrictive in access to their programs and must provide for equal opportunity and access for all individuals.<sup>39</sup> The U.S. Department of Health and Human Services investigates these entities to ensure that there is proper access to the facility for individuals with physical disabilities, or that the entity provides appropriate means for effective communication for those who have hearing, speech, or sight impediments.<sup>40</sup> Based on the outcome of this review, the entity may then be required to either eliminate or revise the standards used in determining if an individual may or may not benefit from the service or program.<sup>41</sup>

These federal statutes were ultimately designed to protect individuals, including those with disabilities, from being excluded from equal opportunity and access to health care. Of course, there may be legitimate and reasonable factors, excluding or due to the disability, to preclude the individual from participating in receiving the benefits from the program. Organ transplantation is not a guaranteed life-saving procedure; complications that impair the

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<sup>37</sup> See *Discrimination on the Basis of Disability*, U.S. DEP'T HEALTH & HUM. SERVS., <http://www.hhs.gov/ocr/civilrights/understanding/disability/> (last visited Mar. 7, 2016).

<sup>38</sup> See *Civil Rights*, U.S. DEP'T HEALTH & HUM. SERVS., <http://www.hhs.gov/ocr/civilrights/index.html> (last visited Mar. 7, 2016); *Resolution Agreements*, *supra* note 25.

<sup>39</sup> *Civil Rights Requirements – C. Civil Rights Laws Applicable to Persons with Disabilities*, U.S. DEP'T HEALTH & HUM. SERVS., <http://www.hhs.gov/civil-rights/for-individuals/special-topics/needy-families/persons-with-disabilities/index.html> (last visited Mar. 7, 2016).

<sup>40</sup> *Id.*

<sup>41</sup> See *id.*

health of the recipient may arise after transplantation.<sup>42</sup> Common health risks, such as cancerous infections or organ rejection, and other medical complications may follow the procedure.<sup>43</sup>

*B. Federal Civil Rights Legislation Defined by the Courts*

The Americans with Disabilities Act (“ADA”) prohibits, in general, discrimination on the basis of disability.<sup>44</sup> But the ADA articulates its prohibition on discrimination on the basis of disability broadly and does not specifically address organ transplantation.<sup>45</sup> In *Olmstead v. L. C.* the U.S. Supreme Court determined that Congress intended for the ADA to resolve the social issue of discrimination against individuals with disabilities.<sup>46</sup> The Court addressed the legislative history of the statutes and congressional intent behind the statutes.<sup>47</sup> The Court found that Title II specifically sought to eradicate the historical discrimination that individuals with disabilities faced when they tried to participate in programs or activities provided by public entities.<sup>48</sup> Furthermore, it found that “Congress instructed the Attorney General to issue regulations implementing provisions of Title II, including § 12132’s discrimination proscription.”<sup>49</sup> The Attorney General is required to

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<sup>42</sup> *Transplant Problems That May Show Up Later*, AM. CANCER SOC’Y, <http://www.cancer.org/treatment/treatmentsandsideeffects/treatmenttypes/bonemarrowandperipheralbloodstemcelltransplant/stem-cell-transplant-long-term-problems-after-transplant> (last visited Mar. 7, 2016).

<sup>43</sup> See *infra* Section II.C.

<sup>44</sup> See 42 U.S.C. § 12101 (2012) (describing the purpose of the Act “to provide clear, strong, consistent, enforceable standards of addressing discrimination against individuals with disabilities” due to historical evidence of how people with physical and/or mental disabilities have been prevented from enjoying the right “to fully participate in all aspects of society” and that they have been often unable to afford any “legal recourse to redress such discrimination”).

<sup>45</sup> See 42 U.S.C. § 12132 (2012) (prohibiting discrimination on the basis of disability, but does not discuss healthcare in regards to organ transplantation).

<sup>46</sup> *Olmstead v. L.C.*, 527 U.S. 581, 588–89 (1999).

<sup>47</sup> See *id.* at 588–92 (discussing the introductory provisions of the ADA and the pervasive societal problem of segregating individuals with disabilities which the statute sought to eliminate).

<sup>48</sup> *Id.* at 589–90.

<sup>49</sup> *Id.* at 591; see 42 U.S.C. § 12134(a) (2012).

incorporate regulations that would be applicable to entities receiving federal financial assistance, such as Section 504.<sup>50</sup> The Court recognized that both Title II and Section 504 compel public entities and federally funded entities to “administer programs and activities in the most integrated setting appropriate to the needs of qualified handicapped persons.”<sup>51</sup>

In *Olmstead*, two women were diagnosed with different cognitive disabilities and were voluntarily admitted to Georgia Regional Hospital where they were evaluated by a team of physicians at different times.<sup>52</sup> After their psychiatric conditions had stabilized, their treating physicians concluded that they could be treated in a community-based setting.<sup>53</sup> Despite these evaluations, both women remained involuntarily institutionalized in a segregated environment.<sup>54</sup> The women filed suit contending that the State discriminated by reason of their disabilities.<sup>55</sup> The Supreme Court affirmed the Eleventh Circuit’s holding that “upheld the Attorney General’s construction of the ADA” which concluded that the actions of the State “constitute[d] a form of discrimination based on disability prohibited by Title II.”<sup>56</sup> Therefore, the Supreme Court has recognized that cognitive disabilities are disabilities that fall within Title II and Section 504’s protections.

Some lower federal courts have similarly interpreted the term “disability” in the federal statutes to include a broad array of disabilities, including cognitive disabilities. For example, in *Kinney v. Yerusolim*,<sup>57</sup> the Third Circuit affirmed the district court’s interpretation when it was faced with the issue of implementing the ADA in Philadelphia.<sup>58</sup> The district court recognized that Congress

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<sup>50</sup> *Olmstead*, 527 U.S. at 591.

<sup>51</sup> *Id.* at 591–92 (citing 28 C.F.R. § 41.51(d)).

<sup>52</sup> *Id.* at 593.

<sup>53</sup> *Id.*

<sup>54</sup> *Id.*

<sup>55</sup> *See id.* at 593–94.

<sup>56</sup> *Id.* at 596–97.

<sup>57</sup> *Kinney v. Yerusolim*, 812 F. Supp. 547 (E.D. Pa. 1993).

<sup>58</sup> *Kinney v. Yerusolim*, 9 F.3d 1067, 1075 (3d Cir. 1993); *see Kinney*, 812 F. Supp. at 548. The plaintiffs were disabled individuals who sought to compel the city to install accessible areas to accommodate their disabilities on all streets

had passed the ADA, specifically Title II, “to address the problem of discrimination against persons with disabilities” from participating or receiving the benefits of public services by a public entity.<sup>59</sup> The court further recognized that the ADA requirements “directed the Department of Justice . . . to promulgate regulations consistent with the anti-discrimination provisions of Section 504 of the Rehabilitation Act of 1973” which prohibit discrimination that precludes any individual that is handicapped to participate in programs that receive federal funds.<sup>60</sup> The court found that the statute should be construed broadly due to the fact that the purpose of the ADA was to “eliminate discrimination against the disabled in all facets of society” and in order to effectuate this remedial statute’s purposes.<sup>61</sup> This may be an indication that the court intended to protect those who are physically and/or mentally disabled in every public and social aspect, essentially in the rights that every well-abled person enjoys.<sup>62</sup>

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that had been resurfaced since the effective date of the ADA. *Kinney*, 812 F. Supp. at 548.

<sup>59</sup> *Kinney*, 812 F. Supp. at 548.

<sup>60</sup> *Id.*; see also 29 U.S.C. § 794 (2012).

<sup>61</sup> *Kinney*, 812 F. Supp. at 551. The court deferred to congressional intent for the purpose of protecting those who have historically endured the hindrances of discrimination. See *id.* at 548 (“The removal of architectural barriers to the disabled . . . was a major concern of Congress in passing the ADA.”).

<sup>62</sup> See *id.* at 548 (deferring to Congress for interpretation of Title II, 42 U.S.C. § 12131). Some have argued, such as Assemblyman Villaraigosa during a senate committee hearing in California, that even though the ADA intends to protect individuals with disabilities from such discrimination, court interpretation is required on areas where it is silent. S. HEALTH & HUMAN SERVS. COMM. AB 2861, 1995–1996 Leg. Reg. Sess. (Cal. 1996), [http://www.leginfo.ca.gov/pub/95-96/bill/asm/ab\\_2851-2900/ab\\_2861\\_cfa\\_960523\\_113041\\_sen\\_comm.html](http://www.leginfo.ca.gov/pub/95-96/bill/asm/ab_2851-2900/ab_2861_cfa_960523_113041_sen_comm.html).

Assemblyman Villaraigosa’s concern was in regards to the Sandra Jensen case in California, where a woman with Down Syndrome was denied a heart-lung transplant solely on the basis of her disability. *Id.* Sandra Jensen’s case brought to light the issue of organ transplant eligibility discrimination on the basis of mental disability. See Bruce Kappel, *Lives Worth Saving: Organ Transplantation and People with Disabilities*, MNDDC (June 2004), <http://mn.gov/mnddc/news/newsitems/transplant.html>. Sandra Jensen was the first person with Down Syndrome to receive a heart-lung transplant. *Id.*

## II. THE ORGAN TRANSPLANTATION PROCESS AND DIFFICULTIES

A. *The National Organ Transplant Act, Organ Procurement, and Transplantation Network and United Network for Organ Sharing*

Organ transplantation is a potentially life-saving process.<sup>63</sup> However, historically, there has been a critical scarcity in organ donation.<sup>64</sup> To address this issue and improve organ matching and placement, Congress passed the National Organ Transplant Act (“NOTA”) in 1984.<sup>65</sup> The Act applies to all organ transplant centers, including federally funded entities as well as private and non-profit organizations that are under federal contract.<sup>66</sup> NOTA “made it a crime ‘for any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation if the transfer affects interstate commerce.’”<sup>67</sup> Congress acknowledged that an organ market would portray human body parts as commodities by distributing organs across state borders.<sup>68</sup> A larger market could coerce organ donors to sell their organs.<sup>69</sup>

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<sup>63</sup> *Organ and Tissue Donation*, HEALTH DIRECT, <http://www.healthdirect.gov.au/organ-and-tissue-donation> (last visited Mar. 7, 2016); *Treatment and Procedures*, CLEVELAND CLINIC, [https://my.clevelandclinic.org/health/treatments\\_and\\_procedures/hic\\_Organ\\_Donation\\_and\\_Transplantation](https://my.clevelandclinic.org/health/treatments_and_procedures/hic_Organ_Donation_and_Transplantation) (last visited Mar. 7, 2016). See generally LIFE CENTER NORTHWEST, <http://www.lcnw.org/donation/how-does-the-donation-process-work/> (last visited Mar. 7, 2016).

<sup>64</sup> See *Organ Procurement and Transplantation Network: History & NOTA*, U.S. DEP’T HEALTH & HUM. SERVS., <http://optn.transplant.hrsa.gov/governance/about-the-optn/history-nota/> (last visited Mar. 7, 2016) [hereinafter *OPTN History*]; see also *Treatment and Procedures*, *supra* note 63.

<sup>65</sup> *OPTN History*, *supra* note 64.

<sup>66</sup> *Id.*; see also *Fact Sheet Section 504*, *supra* note 18.

<sup>67</sup> Gwen Mayes, *Buying and Selling Organs for Transplantation in the US: National Organ Transplant Act of 1984 (NOTA) Bans Buying and Selling*, MEDSCAPE, [http://wwwwww.medscape.org/viewarticle/465200\\_2](http://wwwwww.medscape.org/viewarticle/465200_2) (last visited Mar. 7, 2016) (quoting National Organ Transplant Act § 301).

<sup>68</sup> *OPTN History*, *supra* note 64; see National Organ Transplant Act, Pub. L. No. 98-507, 98 Stat. 2339 (1984).

<sup>69</sup> See Mayes, *supra* note 67.

Additionally, NOTA established the Organ Procurement and Transplantation Network (“OPTN”) so that an organ transplantation system across the nation will maintain a national registry for efficient organ matching and allocation.<sup>70</sup> The Department of Health and Human Services’ Health Resources and Services Administration (“HRSA”)<sup>71</sup> has indicated that the OPTN policies require that organ transplant centers provide the inclusion and exclusion criteria they use in the evaluation process for an individual who seeks to become a transplant candidate.<sup>72</sup> These criteria generally describe the characteristics that the organ transplant center will review and evaluate in order to decide whether a patient is an acceptable candidate for transplant, or if the patient will not be considered as a candidate to be placed on the waitlist.<sup>73</sup>

Frequently, an individual may be denied placement on the waitlist because non-medical factors such as habits or daily lifestyle may be detrimental to the lifespan of the individual or organ received.<sup>74</sup> Medical factors are also taken into consideration in order

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<sup>70</sup> *OPTN History*, *supra* note 64; *see Organ Transplantation: The Process*, U.S. DEP’T OF HEALTH & HUM. SERVS., <http://www.organdonor.gov/about/transplantprocess.html> (last visited Mar. 7, 2016).

<sup>71</sup> “The OPTN is administered under contract to the [Department of Health and Human Services] through its Health Resources and Services Administration’s [(“HRSA”)] Division of Transplantation. The OPTN contract is currently held by the United Network for Organ Sharing (UNOS) which has been the contractor since 1986.” *Organ Transplantation: The Process*, *supra* note 70.

<sup>72</sup> *See* 42 C.F.R. § 121.6(c) (2015) (“Transplant programs shall establish criteria for organ acceptance, and shall provide such criteria to the OPTN and the OPOs with which they are affiliated.”).

<sup>73</sup> *See id.* § 121.6–7.

<sup>74</sup> *See General Considerations in Assessment for Transplant Candidacy*, U.S. DEP’T HEALTH & HUM. SERVS., <http://optn.transplant.hrsa.gov/resources/ethics/general-considerations-in-assessment-for-transplant-candidacy/> (last visited Mar. 7, 2016). For an example of selection criteria considered in an evaluation for transplantation, *see Transplant Center: The Evaluation Process*, UC DAVIS HEALTH SYS., [http://www.ucdmc.ucdavis.edu/transplant/learnabout/learn\\_eval\\_process.html](http://www.ucdmc.ucdavis.edu/transplant/learnabout/learn_eval_process.html) (last visited Mar. 7, 2016) (“Smokers may be declined until they are able to quit . . . . Candidates must be motivated, have demonstrated compliance with medical and dialysis regimens, . . . live in a stable environment capable of

to decrease the risk of complications like cancerous infections and organ or host rejection post-transplant.<sup>75</sup>

*B. Organ Procurement: Difficulties of Procuring an Organ Transplant – The Waitlist*

In order for an individual to procure an organ transplant, they must first receive a referral from their physician to be evaluated by the transplant facility.<sup>76</sup> Those seeking referrals typically do so because the individual's organ failure is near its end stage, and transplantation is the only remaining treatment.<sup>77</sup> Next, a transplant team at the facility determines whether the individual is eligible to be a candidate on the organ transplant waitlist.<sup>78</sup> Ultimately, “[t]he hospital's transplant team—a panel of physicians and other professionals involved in the transplant process—makes the . . . decision as to whether an individual is a good candidate” to be placed on the waitlist, or if the individual should be refused such placement.<sup>79</sup> The United Network for Organ Sharing (“UNOS”), the sole OPTN contractor since 1986,<sup>80</sup> manages the database of all

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supporting compliance with the transplant regimen . . . and not be an active substance abuser.”).

<sup>75</sup> For information on medical complications post-transplantation, see DEBATING SCI. ISSUES, ORGAN TRANSPLANTATION [http://www.debatingscienceissues.com/wp-content/uploads/2013/01/ORGAN\\_TRANSPLANTATION\\_print-friendly.pdf](http://www.debatingscienceissues.com/wp-content/uploads/2013/01/ORGAN_TRANSPLANTATION_print-friendly.pdf) (last visited Mar. 7, 2016).

<sup>76</sup> *The National Waiting List*, UNOS TRANSPLANT LIVING, <http://www.transplantliving.org/before-the-transplant/getting-on-the-list/the-national-waiting-list/> (last visited Mar. 7, 2016).

<sup>77</sup> See *Human Organ Transplantation*, WORLD HEALTH ORG., <http://www.who.int/transplantation/organ/en/> (last visited Mar. 7, 2016).

<sup>78</sup> *The National Waiting List*, *supra* note 76.

<sup>79</sup> ARI NE'EMAN ET AL., ORGAN TRANSPLANTATION AND PEOPLE WITH I/DD: A REVIEW OF RESEARCH, POLICY AND NEXT STEPS, AUTISTIC SELF ADVOCACY NETWORK 5 (Mar. 2013), [http://autisticadvocacy.org/wp-content/uploads/2013/03/ASAN-Organ-Transplantation-Policy-Brief\\_3.18.13.pdf](http://autisticadvocacy.org/wp-content/uploads/2013/03/ASAN-Organ-Transplantation-Policy-Brief_3.18.13.pdf). Additionally, “[t]he rules that dictate the waiting list vary by organ.” *Understanding the Organ Transplant Waiting List*, GIFT OF LIFE DONOR PROGRAM, <http://www.donors1.org/patient/waitinglist/#1> (last visited Mar. 7, 2016).

<sup>80</sup> *Organ Transplantation: The Process*, *supra* note 70.

patients that are waiting for an organ.<sup>81</sup> The waiting time for an organ match and procurement varies depending on the organ.<sup>82</sup> The matching process also depends on several factors such as the blood type of the organ donor and the individual and the distance between the individual and the hospital.<sup>83</sup>

The UNOS Ethics Committee recognizes that severely limited availability of organs requires an efficient way to determine the probability of extending an individual's life after a transplant operation.<sup>84</sup> The Committee requires that a transplant facility's physicians maintain ethical and "moral obligations to extend life and relieve suffering" and "recognize the limitations of transplantation in meeting these ends."<sup>85</sup> After the evaluating physician deems an individual eligible for an organ transplant, they place him or her on the OPTN national waitlist.<sup>86</sup>

A spot on the national waitlist, however, does not guarantee a transplant. Because of the scarcity of donated organs, those on the list often die while waiting for a match.<sup>87</sup> The American Transplant Foundation estimates that over 121,000 people in the United States are on the waitlist for an organ transplant.<sup>88</sup> Of those people, more than 6,500 people die a year waiting for an available organ.<sup>89</sup> In 2012 alone, 321 people died waiting for a new heart and in 2013 the waitlist contained 3,500 individuals. The waitlist continues to grow as the number of available organs remains approximately the

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<sup>81</sup> *Understanding the Organ Transplant Waiting List*, *supra* note 79.

<sup>82</sup> *See id.* (reporting that the average median wait time for a kidney is 5 years, a liver is 11 months, a heart is 4 months, a lung is 4 months, a kidney is 1.5 years, and a pancreas is 2 years).

<sup>83</sup> *Organ Matching Process*, U.S. DEP'T HEALTH & HUM. SERVS., <http://www.organdonor.gov/about/organmatching.html> (last visited Mar. 7, 2016).

<sup>84</sup> *See General Considerations in Assessment for Transplant Candidacy*, *supra* note 74.

<sup>85</sup> *Id.*

<sup>86</sup> *Organ Transplantation: The Process*, *supra* note 70.

<sup>87</sup> *The Need is Real: Data*, U.S. DEP'T HEALTH & HUM. SERVS., <http://www.organdonor.gov/about/data.html> (last visited Mar. 7, 2016).

<sup>88</sup> *Facts and Myths*, AM. TRANSPLANT FOUND., <http://www.americantransplantfoundation.org/about-transplant/facts-and-myths/> (last visited Mar. 7, 2016).

<sup>89</sup> *Id.*



same.<sup>90</sup> The scarcity of organs forces physicians to evaluate patients closely and select those most likely to receive the longest and highest quality of life from a new organ.<sup>91</sup>

### C. Risks Subsequent to an Organ Transplantation

While organ transplantation is a “life-saving therapy for patients with end-stage organ disease,”<sup>92</sup> it also results in an increased health risk to the organ recipient.<sup>93</sup> Organ transplant recipients are at high risk of developing cancer,<sup>94</sup> as well as other medical complications such as organ rejection and infections due to immunosuppressant medications.<sup>95</sup> Organ transplant recipients must take immunosuppressant medications to reduce the risk of their bodies rejecting the new organ.<sup>96</sup> Studies have shown that immune suppression is associated with an increased risk of some cancers.<sup>97</sup>

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<sup>90</sup> Cohen, *supra* note 1.

<sup>91</sup> See Allison Tong et al., *Rationing Scarce Organs for Transplantation: Healthcare Provider Perspectives on Wait-Listing and Organ Allocation*, 27 CLINICAL TRANSPLANTATION 60, 60 (2013) (stating that physicians have a duty to determine “how to maximize the benefit of scarce organs while maintaining equity of access to transplantation . . . . Achieving equity mean[s] all patients should have an equal chance of transplant”).

<sup>92</sup> *NIH Study Finds Broad Spectrum of Cancer Risk for Organ Transplant Recipients in U.S.*, NAT’L CANCER INST. (Nov. 1, 2011), <http://www.cancer.gov/news-events/press-releases/2011/OrganTransplantCancerRisk> [hereinafter *NIH Study*].

<sup>93</sup> See Israel Penn, *Cancers Complicating Organ Transplantation*, 323 NEW ENG. J. MED. 1767, 1767 (1990).

<sup>94</sup> *Id.*; *NIH Study*, *supra* note 92.

<sup>95</sup> *Potential Risks of Transplant Surgery*, UC DAVIS TRANSPLANT CTR., [http://www.ucdmc.ucdavis.edu/transplant/learnabout/learn\\_risks.html](http://www.ucdmc.ucdavis.edu/transplant/learnabout/learn_risks.html) (last visited Mar. 7, 2016).

<sup>96</sup> *Possible Kidney Transplant Complications*, EMORY HEALTHCARE, <http://www.emoryhealthcare.org/transplant-kidney/learn-about/possible-complications.html> (last visited Mar. 7, 2016); see also *Kidney Transplant Rejection*, U. MISS. MED. CTR., [https://www.ummhealth.com/health\\_care\\_services/transplant/adult/kidney\\_transplant/current\\_transplant\\_recipients/kidney\\_rejection/kidney\\_rejection.aspx](https://www.ummhealth.com/health_care_services/transplant/adult/kidney_transplant/current_transplant_recipients/kidney_rejection/kidney_rejection.aspx) (last visited Mar. 7, 2016).

<sup>97</sup> Claire M. Vajdic & Marina T. van Leeuwen, *Cancer Incidence and Risk Factors After Solid Organ Transplantation*, 125 INT’L J. CANCER 1747, 1747

According to the National Institute of Health, these medications create a cancer risk that “resembles that of people with HIV infection.”<sup>98</sup> The recipient’s body may also overcome the effects of the medication and reject the new organ.<sup>99</sup> An individual’s own susceptibility to infection may also impact his or her risk of complication.<sup>100</sup>

Certain genetic defects may also put individuals at a higher risk for tumors and infections after organ transplantation.<sup>101</sup> Studies have shown that children with Down syndrome have an immune system that “is intrinsically deficient from the very beginning.”<sup>102</sup> Due to the fact that children with Down syndrome have poor immune systems, “[t]ransplant experts have expressed concern that post-transplant immunosuppressant medications might increase the risk of mortality significantly more in post-transplant patients with Down syndrome than in post-transplant patients generally.”<sup>103</sup> Thus, Down syndrome may increase the risk for development of cancer or infection after organ transplantation.<sup>104</sup>

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(2009); see Jacques Dantal & Jean-Paul Souillou, *Immunosuppressive Drugs and the Risk of Cancer After Organ Transplantation*, 352 NEW ENG. J. MED. 1371, 1371 (2005) (“As compared with an age-matched healthy population or with patients undergoing dialysis, organ-transplant recipients have an increased incidence of cancer.”).

<sup>98</sup> NIH Study, *supra* note 92.

<sup>99</sup> See *Possible Kidney Transplant Complications*, *supra* note 96; see also *Organ Rejection After Renal Transplant*, COLUMBIA U. MED. CTR., <http://columbiasurgery.org/kidney-transplant/organ-rejection-after-renal-transplant> (last visited Mar. 7, 2016); *Kidney Transplant Rejection*, *supra* note 96.

<sup>100</sup> Jay A. Fishman, M.D., *Infection in Solid-Organ Transplant Recipients*, 357 NEW ENG. J. MED. 2601, 2601 (2007).

<sup>101</sup> See *Intrinsic Defect of the Immune System in Children with Down Syndrome: A Review*, J. TRANSLATIONAL IMMUNOLOGY, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2759463/> (last visited Mar. 7, 2016); see also Cohen, *supra* note 1.

<sup>102</sup> See *Intrinsic Defect of the Immune System in Children with Down Syndrome: A Review*, *supra* note 101.

<sup>103</sup> Marilee A. Martens et al., *Organ Transplantation, Organ Donation and Mental Retardation*, 10 PEDIATRIC TRANSPLANTATION 658, 661 (2006).

<sup>104</sup> Helen Leonard et al., *Heart and Heart-Lung Transplantation in Down’s Syndrome*, NCBI (Mar. 25, 2000), <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1127180/> (“Well documented

In certain situations, doctors have a legitimate reason to preclude those with cognitive disabilities, such as Down syndrome, from receiving an organ transplant. Due to the fact that there are medical concerns linking Down syndrome and organ transplantation that pose a higher risk to these individuals, it is in their best interest for them to not receive organ transplants. Similarly, cognitive disabilities that result in a weaker immune system would give doctors reason to consider refusing the individual with the opportunity of transplantation since health risks after transplantation are directly caused by a weak immune system.<sup>105</sup>

As discussed above, Maverick's doctors rejected his candidacy for transplantation based on his CSS.<sup>106</sup> The doctors stated that Maverick's "genetic defect is associated with increased infections and tumors, which would be greatly magnified combined with immunosuppression involved in transplantation," and that "he does not qualify to be a heart transplant candidate . . . based on the medical implications of his [CSS], which would limit his survival and potential benefit from transplantation."<sup>107</sup> On the contrary, the doctors provided information about CSS to Maverick's parents that cited to a study conducted by Dr. Gijs Santen.<sup>108</sup> When Maverick's mother contacted Dr. Gijs Santen, a clinical geneticist,<sup>109</sup> to inquire about Maverick's condition, Dr. Santen responded that children with CSS do not have compromised immune systems.<sup>110</sup> Dr. Santen further reported to CNN that "[t]here is no objective problem with the immune system (in children with [CSS])" and that "infection risk [would not be] a reason not to perform a heart transplant."<sup>111</sup> Studies

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immunological abnormalities in Down's syndrome result in a high incidence of infection, autoimmune disease, and malignancy.").

<sup>105</sup> See Fishman, *supra* note 100.

<sup>106</sup> See Cohen, *supra* note 1.

<sup>107</sup> *Id.*

<sup>108</sup> *Id.*

<sup>109</sup> Julie S., *Baby Denied of Heart Transplant Because He Has Rare, Genetic Disease*, HNGN (Dec. 1, 2013), <http://www.hngn.com/articles/18479/20131201/baby-denied-of-heart-transplant-because-he-has-rare-genetic-disease.htm>.

<sup>110</sup> Cohen, *supra* note 1.

<sup>111</sup> *Id.*; James Nye, *Parents' Outrage as They Claim Doctors Denied Their Baby Son a Life-Saving Heart Transplant Operation 'Because He is Disabled'*,

have shown that individuals with CSS have symptoms such as distinctive craniofacial and skeletal abnormalities, delays in weight gain, frequent respiratory infections, and intellectual disabilities.<sup>112</sup> However, as Dr. Santen stated, while CSS may affect several body systems, there has been no finding that individuals with CSS have a deficiency with their immune system.<sup>113</sup> Studies have similarly shown that transplant recipients with CSS do not have any increased risk of developing cancer.<sup>114</sup> These conflicting conclusions highlight how stories like Maverick's raise questions as to whether doctors are given too much discretion as to who is eligible to receive organ transplants.

### III. THE AUTISTIC SELF ADVOCACY NETWORK'S POLICY BRIEF AND STATE LEGISLATURES

Although legal bright-line rules are difficult to formulate in regards to such a convoluted topic as organ procurement for cognitively disabled patients, some advocacy organizations have formulated policy outlines of legal guidelines that provide direction. These policies provide a clearer set of guidelines for physicians who face these issues.<sup>115</sup> The Autistic Self Advocacy Network ("ASAN") is a non-profit organization that advocates for the rights

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DAILY MAIL (Nov. 30, 2013), <http://www.dailymail.co.uk/news/article-2516085/Parents-outrage-baby-son-denied-heart-transplant-disabled.html>.

<sup>112</sup> *Coffin Siris Syndrome*, *supra* note 7; Samantha A. Schrier et al., *The Coffin-Siris Syndrome: A Proposed Diagnostic Approach and Assessment of 15 Overlapping Cases*, NCBI (June 18, 2012), <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3402612/>; *Coffin-Siris Syndrome*, GENETICS HOME REFERENCE (May 2013), <http://ghr.nlm.nih.gov/condition/coffin-siris-syndrome>.

<sup>113</sup> Nye, *supra* note 111; *see also Coffin Siris Syndrome*, *supra* note 7; Schrier et al., *supra* note 112; *Coffin-Siris Syndrome*, *supra* note 112.

<sup>114</sup> *See* Cohen, *supra* note 1; *see also* Samantha Schrier Vergano et al., *Coffin-Siris Syndrome*, NCBI, <http://www.ncbi.nlm.nih.gov/books/NBK131811/> (last updated May 12, 2016) (explaining that there is a "rarity of tumors in CSS"). CNN conducted interviews with six experts on CSS, including Dr. Santen. Cohen, *supra* note 1. The six experts, including one of the founders of the syndrome, Dr. Grange Coffin, agreed that children with CSS do not have compromised immune systems and that CSS is not "a valid reason to deny a patient a transplant." *Id.*

<sup>115</sup> *See ASAN Antidiscrimination Bill*, *supra* note 16.

of persons with autism.<sup>116</sup> In March 2015, ASAN collaborated with some advocacy groups and community service groups in Maryland to advocate for an anti-organ transplant discrimination bill.<sup>117</sup> The Senate Bill addressed the issue of how people with disabilities encounter discrimination when they seek life-saving organ transplantation.<sup>118</sup> The legislation would ban disability-based discrimination in organ transplantation.<sup>119</sup>

The bill's solution is to clarify that healthcare providers are prohibited from refusing or denying services, such as organ transplantation, "solely on the basis of a qualified individual's disability."<sup>120</sup> It also requires that healthcare providers take into consideration every support available to assist an individual with a disability to manage proper care after the procedure, and "include a . . . procedure [that would] ensure that people in [critical] need of an organ transplant can obtain timely resolutions to their

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<sup>116</sup> *About, AUTISTIC SELF ADVOCACY NETWORK*, <http://autisticadvocacy.org/home/about-asan/> (last visited Mar. 7, 2016).

<sup>117</sup> *See ASAN Antidiscrimination Bill*, *supra* note 16 (listing advocacy and community service groups, including The Arc Maryland, Maryland Association of Community Services, Maryland Developmental Disabilities Council, Maryland Disability Law Center, People On The Go, Independence Now, National Down Syndrome Society, and Maryland Down Syndrome Advocacy Coalition).

<sup>118</sup> *Id.*

<sup>119</sup> *See id.*

According to the policy brief, "[l]egislation . . . should explicitly include the following points: (a) a prohibition against discriminating against people with disabilities that are not medically relevant to the transplantation process; (b) clarification that support services should be considered when assessing the ability of a transplantation candidate to comply with postoperative procedures, and (c) the scope of services and health care interactions relevant to the law, including referrals, evaluation and recommendation for access to the transplantation list.'

*Maryland Enacts Law Banning Disability-Based Discrimination in Organ Transplantation*, NASDDDS (Mar. 29, 2015), <http://www.nasddd.org/news/maryland-enacts-law-banning-disability-based-discrimination-in-organ-transp/> [hereinafter *Maryland Enacts Law*].

<sup>120</sup> *ASAN Antidiscrimination Bill*, *supra* note 16.

[discrimination] claims.”<sup>121</sup> This solution provides doctors with clarity so that they may fulfill their obligations and properly determine an individual’s need for transplantation without engaging in discriminatory behavior.

Prior to ASAN’s policy guidelines, some states adopted legislation to provide protection for individuals with cognitive disabilities from discrimination in organ transplantation.<sup>122</sup> “California was the first state to provide statutory protection for intellectually disabled individuals seeking organ transplants.”<sup>123</sup> In 1995, Sandra Jensen, a thirty-four year old with Down syndrome, sought a heart-lung transplant.<sup>124</sup> Transplant centers denied Sandra because physicians did not want to “risk wasting scarce organs on someone who might not be able to follow the complicated regimen of post-transplant drugs.”<sup>125</sup> Many found this rejection discriminatory and unacceptable, and, consequently, the hospitals relented and gave Sandra the transplant that she needed.<sup>126</sup> As a result, to avoid further discrimination on the basis of intellectual disability, California passed legislation prohibiting such discrimination in organ transplantation.<sup>127</sup> The California Statute, §7151.35(a), provides that:

No hospital, physician and surgeon, procurement organization, or other person shall determine the ultimate recipient of an anatomical gift based upon a potential recipient’s physical or mental disability,

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<sup>121</sup> *Id.*

<sup>122</sup> See, e.g., CAL. HEALTH & SAFETY CODE § 7151.35 (2015).

<sup>123</sup> Sara Frank, *Eligibility Discrimination of the Intellectually Disabled in Pediatric Organ Transplantation*, 10 J. HEALTH & BIOMED. L. 101, 111 (2014); *ASAN Antidiscrimination Bill*, *supra* note 16; Laura Whelan, *Allocating Organs to Those with Down Syndrome: Compliance as a Scapegoat*, BIOETHICS PROJECT, <http://blogs.kentplace.org/bioethicsproject/2014/02/10/allocating-organs-syndrome-compliance-scapegoat/> (last visited Mar. 7, 2016); see CAL. HEALTH & SAFETY CODE § 7151.35 (2015).

<sup>124</sup> Sheryl Gay Stolberg, *Ideas & Trends: The Unlisted; Live and Let Die Over Transplants*, N.Y. TIMES (Apr. 5, 1998), <http://www.nytimes.com/1998/04/05/weekinreview/ideas-trends-the-unlisted-live-and-let-die-over-transplants.html?src=pm>.

<sup>125</sup> *Id.*

<sup>126</sup> *Id.*

<sup>127</sup> See Frank, *supra* note 123, at 111–13.

except to the extent that the physical or mental disability has been found by a physician and surgeon, following a case-by-case evaluation of the potential recipient, to be medically significant to the provision of the anatomical gift.<sup>128</sup>

In ASAN's policy brief, it recommended that "states should follow California's example and pass legislation explicitly clarifying legal protections against discrimination for people with disabilities seeking transplants."<sup>129</sup> The brief further articulated that supplemental state laws that enacted clearer guidelines in their legislation would remedy the vagueness and difficulty of enforcing federal civil rights law in medical decision-making.<sup>130</sup>

Several years after the Sandra Jensen case, New Jersey passed similar legislation that "prohibit[ed] discrimination of people with developmental disabilities" and ensured that these individuals would receive the necessary medical treatment their conditions may require, such as organ transplants.<sup>131</sup> This legislation was a response to the public outcry over the case of Amelia Rivera, a little girl that was denied a transplant due to her mental capacity.<sup>132</sup> In 2012, Amelia Rivera desperately needed a transplant and, in response, her mother offered her own kidney.<sup>133</sup> Initially, the hospital denied the procedure because Amelia was "mentally retarded" and had "brain damage,"<sup>134</sup> but reversed their decision as soon as the community responded. In support of the family,<sup>135</sup> New Jersey's state legislators passed a law "to prohibit discrimination against people with

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<sup>128</sup> CAL. HEALTH & SAFETY CODE § 7151.35(a) (2015).

<sup>129</sup> NE'EMAN ET AL., *supra* note 79, at 7.

<sup>130</sup> *See id.*

<sup>131</sup> Tim Shriver, *Amelia Rivera, Our Symbol of Justice*, SPECIAL OLYMPICS BLOG (Aug. 21, 2012), <https://specialolympicsblog.wordpress.com/2012/08/21/amelia-rivera-our-symbol-of-justice/>; *see also ASAN Antidiscrimination Bill*, *supra* note 16.

<sup>132</sup> *ASAN Antidiscrimination Bill*, *supra* note 16.

<sup>133</sup> *Id.*

<sup>134</sup> Emily Leaman, *Should CHOP Refuse Transplants for Mentally Retarded Kids?*, PHILA. MAGAZINE, (Jan. 16, 2012), <http://www.phillymag.com/be-well-philly/2012/01/16/chop-refuse-transplants-mentally-retarded-kids/>; *ASAN Antidiscrimination Bill*, *supra* note 16.

<sup>135</sup> *ASAN Antidiscrimination Bill*, *supra* note 16; NE'EMAN ET AL., *supra* note 79, at 4.

disabilities in the context of organ transplantation.”<sup>136</sup> The state legislature, following California’s approach, found that cognitive disabilities fall within the meaning of “disability” that is protected by the ADA and took the extra step of protecting the intellectually disabled through state legislation as well.<sup>137</sup> New Jersey’s statute provides that any individual seeking “an anatomical gift shall not be deemed ineligible to receive an anatomical gift solely because of the individual’s physical or mental disability, except to the extent that the physical or mental disability” is deemed “medically significant” by a physician.<sup>138</sup>

Maryland has also enacted legislation<sup>139</sup> “to ensure [that] people with disabilities have access to life saving transplants.”<sup>140</sup> Furthermore, Maryland’s legislation adopted ASAN’s policy brief,<sup>141</sup> prohibiting disability-based discrimination in organ transplantation.<sup>142</sup> Unlike California and New Jersey, Maryland accomplished this by working proactively towards the issue with the assistance of ASAN and several other advocacy groups. According to ASAN, major transplant centers, such as the University of Maryland, “have removed language from their websites saying that they would not perform transplants for anyone with a ‘severe’

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<sup>136</sup> NE’EMAN ET AL., *supra* note 79, at 5 (“The [New Jersey] legislation . . . prohibits denying a person with a disability referral, evaluation and recommendation for transplantation solely on the basis of a non-medically significant disability and notes that individuals who have the necessary support system to comply with post-transplant medical requirements should not have the inability to independently comply with those requirements held against them when being evaluated for transplantation consideration.”).

<sup>137</sup> Frank, *supra* note 123, at 114–15.

<sup>138</sup> N.J. STAT. § 26:6–86.2 (2015).

<sup>139</sup> *Maryland Enacts Law*, *supra* note 119.

<sup>140</sup> *ASAN Antidiscrimination Bill*, *supra* note 16.

<sup>141</sup> Samantha Crane, *We Wrote It – Now It’s The Law!*, AUTISTIC SELF ADVOCACY NETWORK (Apr. 28, 2015), <http://autisticadvocacy.org/2015/04/we-wrote-it-now-its-the-law/>; *Maryland Enacts Law*, *supra* note 119.

<sup>142</sup> As discussed above, California and New Jersey have adopted such anti-discrimination legislation in response to cases such as Sandra Jensen and Amelia Riveria. On the contrary, Maryland adopted such legislation with the elaborate efforts of ASAN. *See* Crane, *supra* note 141.



developmental or psychiatric disability, regardless of medical need.”<sup>143</sup>

Pennsylvania has also taken a step toward adopting legislation to protect those with cognitive disabilities. In June 2014, State Senator John Sabatina introduced a house bill called “Paul’s Law” in attempts to put an end to “discrimination against people with disabilities who are in need of organ transplants.”<sup>144</sup> Senator Sabatina recognized the disparities that individuals with intellectual disabilities continue to encounter when seeking an organ transplant.<sup>145</sup> The bill was named after an autistic man named Paul Corby, who had a heart condition requiring a transplant.<sup>146</sup> Just like Sandra and Amelia, Paul was denied the transplant due to his cognitive disability.<sup>147</sup> After a large movement on Paul’s behalf, Senator Sabatina introduced the bill to allow programs to “deny transplants to people with disabilities *only* if the disabilities [were] ‘medically significant to the procedure.’”<sup>148</sup> The bill would bar denial to individuals with disabilities merely because they are unable to “comply with complex post-transplant medical regimens as long as they have an adequate support system.”<sup>149</sup>

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<sup>143</sup> Crane, *supra* note 141.

<sup>144</sup> Tony Romeo, *Pa. Lawmaker Wants to Give Disabled Equal Access to Organ Transplants*, CBS PHILLY (June 16, 2014), <http://philadelphia.cbslocal.com/2014/06/16/pa-lawmaker-wants-to-give-disabled-equal-access-to-organ-transplants/>.

<sup>145</sup> *Id.*

<sup>146</sup> *Id.*

<sup>147</sup> See NE’EMAN ET AL., *supra* note 79, at 4.

<sup>148</sup> Chrissy Rivera, *Disabled & Denied Organ Transplant*, PHILLY.COM (July 30, 2015) (emphasis added), [http://articles.philly.com/2015-07-30/news/65001329\\_1\\_amelia-transplant-surgery-kidney](http://articles.philly.com/2015-07-30/news/65001329_1_amelia-transplant-surgery-kidney).

<sup>149</sup> Stacy Burling, *Pa. Bill Would Address Organ-Transplant Discrimination*, PHILLY.COM (Nov. 25, 2013), [http://articles.philly.com/2013-11-25/news/44416148\\_1\\_karen-corby-transplant-list-transplant-program](http://articles.philly.com/2013-11-25/news/44416148_1_karen-corby-transplant-list-transplant-program).

#### IV. ANALYSIS: PHYSICIAN DISCRETION AND DISCRIMINATORY EFFECTS

##### *A. The Discretion of the Physicians Evaluating the Patient for Transplantation Eligibility and its Effects*

The decision to allocate organs takes into account many complicated and interrelated factors which vary from case to case. If research and data demonstrate a correlation between the cognitive disability and a heightened complication risk post-transplantation, then patients should rely on the expertise and discretion of their physicians. However, where the risk is not scientifically and conclusively proven, the physician evaluating the individual should not have absolute discretion to determine transplant eligibility. The physician should disclose that the risks to the individual are unknown, provide the patient with options, and permit the patient to decide whether he should be placed on the waitlist.

The current system of organ allocation provides physicians with too much discretion.<sup>150</sup> Individuals who require organ transplantation are first evaluated by a team of physicians to determine their eligibility to be placed on the waitlist.<sup>151</sup> To determine an individual's eligibility, physicians take into account several psychosocial variables such as "use of illicit drugs, alcohol abuse, mental retardation (IQ [fifty and less]), and documented medical noncompliance."<sup>152</sup> In denying an individual an organ transplant for medical reasons, physicians rely on historical data and research to determine if the transplantation coupled with the type of cognitive disability will increase infection after the procedure.<sup>153</sup>

Because of a lack of federal legislation and hospital guidelines, physicians must utilize their expertise in making eligibility

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<sup>150</sup> Approval from the team of transplant physicians is crucial in the organ allocation process. *See generally* NE'EMAN ET AL., *supra* note 79, at 4–5.

<sup>151</sup> *See supra* Section II.A; *see also* Frank, *supra* note 123, at 115–16 (discussing the role of transplant physicians, transplant teams and hospitals deciding "who is listed for transplant and when they are listed").

<sup>152</sup> Charles E. Canter et al., *AHA Scientific Statement: Indications for Heart Transplantation in Pediatric Heart Disease*, 115 CIRCULATION 658, 668 (2007).

<sup>153</sup> *Id.*

determinations.<sup>154</sup> While the state statutes properly rely on the expertise of well-educated and well-trained physicians in their evaluation process, the prohibition of discrimination on the basis of disability is extremely vague.<sup>155</sup> Section 504 and Title II do not provide for actual protections for those with disabilities in the face of discrimination.<sup>156</sup> Furthermore, federal civil rights legislation does not provide sufficient guidance in the medical field to determine what constitutes “discrimination” in terms of organ transplantation and cognitive disabilities.<sup>157</sup> There is also no system of checks and balances where physicians may be held accountable.<sup>158</sup> Physicians have the ability to claim that an individual is ineligible for candidacy and that it would be in the individual’s best interest to not acquire an organ transplant.

Hospitals, however, lack guidelines<sup>159</sup> that define what would be in the individual’s “best interest,” which ultimately leaves physicians with too much discretion and a lack of guidance and accountability.

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<sup>154</sup> Depending on the type of organ that is needed for transplantation, different physicians with different expertise areas would tend to the patient. *See generally Departments and Centers: Transplant Center*, MAYO CLINIC, <http://www.mayoclinic.org/departments-centers/transplant-center/expertise-innovation-research/living-donor-transplantation> (last visited Mar. 7, 2016); *see also Areas of Expertise*, TRANSPLANTATION: UC SAN DIEGO HEALTH CTR., <http://health.ucsd.edu/specialties/surgery/transplant/areas-expertise/Pages/default.aspx> (last visited Mar. 7, 2016) (discussing UC San Diego Health Center’s various organ transplantation specialty programs).

<sup>155</sup> *See supra* Section I.B.

<sup>156</sup> *See supra* Section I.A.

<sup>157</sup> *See* Frank, *supra* note 123.

<sup>158</sup> Section 504 and Title II exist to protect individuals with disabilities from discrimination by healthcare providers. *See generally* 29 U.S.C. § 794; 42 U.S.C. §§ 12131–12165 (2011). As discussed in Section II.C, other than a compliance review conducted by the U.S. Department of Health and Human Services, physicians are not held accountable for their actions. Non-compliance may result in sanctions; however, these compliance reviews are generally only implemented once someone has filed a valid and credible complaint to the agency. *See supra* Section II.C.

<sup>159</sup> *See supra* Section II.C.

*B. Discrimination*

As New Jersey's Senate President Steve Sweeney stated, "[p]eople with developmental disabilities should not be treated as second-class citizens . . . . They should be afforded the same rights as anyone would want when entering a hospital."<sup>160</sup> There may be medically viable reasons for denying individuals candidacy for an organ transplant.<sup>161</sup> However, categorizing all individuals with cognitive disabilities as "high-risk" for infections or medical complications raises the potential for discrimination. Since federally funded and public entities are required to abide by federal civil rights laws, these entities should be working to comply with these regulations.<sup>162</sup> Of course, physicians may deny organs to some individuals due to the fact that they may partake in habits such as excessive alcohol consumption or smoking.<sup>163</sup> However, some transplant centers will continue to consider these individuals by requiring them to undergo certain programs to prove that they have reformed with a new lifestyle, and be reconsidered for candidacy.<sup>164</sup> Those who are born with cognitive disabilities do not have this option, and broadly denying them the ability to procure an organ transplant denies them access to healthcare simply because of their disability.<sup>165</sup>

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<sup>160</sup> Shriver, *supra* note 131; see *ASAN Antidiscrimination Bill*, *supra* note 16.

<sup>161</sup> See *supra* Section II.C.

<sup>162</sup> See *supra* Section I.A.

<sup>163</sup> See *supra* Section II.A; *General Considerations in Assessment for Transplant Candidacy*, U.S. DEP'T HEALTH & HUM. SERVS., <http://optn.transplant.hrsa.gov/resources/ethics/general-considerations-in-assessment-for-transplant-candidacy/> (last visited Mar. 7, 2016); *Transplant Center: The Evaluation Process*, *supra* note 74.

<sup>164</sup> See *Transplant Center: The Evaluation Process*, *supra* note 74.

<sup>165</sup> ROSA EHRENREICH & JAMIE FELLNER, HUMAN RIGHTS WATCH, MENTAL RETARDATION: AN OVERVIEW (Mar. 2001), <https://www.hrw.org/reports/2001/ustat/ustat0301-01.htm> ("Mental retardation is a lifelong condition of impaired or incomplete mental development."); Brenda Patoine, *Mental Retardation: Struggle, Stigma, Science*, DANA FOUND. (Apr. 1, 2005), [http://www.dana.org/Cerebrum/2005/Mental\\_Retardation\\_\\_Struggle,\\_Stigma,\\_Science/](http://www.dana.org/Cerebrum/2005/Mental_Retardation__Struggle,_Stigma,_Science/) ("No therapy is proven effective for mental retardation; no pill can improve intellectual functioning.").

In any event, physicians have a moral and ethical obligation to extend life to the best of their ability and, with regards to organ transplantation, must recognize the scarcity of organs.<sup>166</sup> Patients with common forms of cognitive disabilities<sup>167</sup> that do carry an abnormally high-risk for medical complications after any transplant procedure would be understandably denied for candidacy. However, in cases where the patient's form of cognitive disability is rare, as was the case with Maverick, and there is conflicting research on whether a transplant will increase risk of complications like organ rejection, infection, or host rejection, there should be limits on the doctor's discretion.<sup>168</sup> It is important that the federal government or individual state governments implement new laws, similar to California's or New Jersey's model, or federal agencies create guidelines that ensure that doctors will make efficient and objective decisions based on the best interests of the patient and not on a subjective discretionary evaluation.

Healthcare providers, both federally funded and public entities, are already bound by Section 504 and Title II and are prohibited from discriminating on the basis of disability.<sup>169</sup> However, these statutes<sup>170</sup> are insufficient to prevent such discrimination from occurring. While these federal statutes may provide an explicit form of protection for the intellectually disabled,<sup>171</sup> there is a lack of guidance for physicians who encounter these issues that call for their discretion in making difficult decisions to place an individual on the waitlist as a valid candidate for organ transplant.

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<sup>166</sup> See *supra* Section II.B.

<sup>167</sup> See *supra* Section II.C.

<sup>168</sup> See Cohen, *supra* note 1.

<sup>169</sup> See *supra* Section I.A.; NE'EMAN ET AL., *supra* note 79, at 5.

<sup>170</sup> See *supra* Section II.B.

<sup>171</sup> See *supra* Section I.A.

V. RECOMMENDATIONS: WHY A POLICY SIMILAR TO THE AUTISTIC SELF-ADVOCACY NETWORK'S FRAMEWORK SHOULD BE ADOPTED FEDERALLY

A. *Judicial Intervention*

As discussed in Section I.B, courts have deferred to Congress for interpreting Title II and Section 504.<sup>172</sup> In *Olmstead*, the Supreme Court found that Congress intended for Title II and Section 504 to protect individuals with cognitive disabilities from discrimination.<sup>173</sup> However, the Court did not provide clear guidelines as to what constitutes discrimination in regards to making medical decisions in organ transplantation. Moving forward, courts can address this issue by providing this type of guidance to physicians making transplant eligibility decisions. In appropriate instances courts should intervene and decide whether healthcare providers are providing enough evidence to prove that they are genuinely denying an individual with a cognitive disability for a legitimate medical reason. Although the judiciary should defer to the expertise of medical professionals, it should not do so at the expense of the civil rights of the cognitively disabled.

On the contrary, court intervention may not be the best alternative in addressing this issue due to the fact that any individual diagnosed with a life-threatening illness that requires immediate medical intervention would have to wait for an inconclusive amount of time for their case to be heard in court.<sup>174</sup> While civil rights law may extend protection for people with disabilities, the difficulties of enforcing such laws to provide access to life-saving procedures have

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<sup>172</sup> See *supra* Section I.B.

<sup>173</sup> *Olmstead v. L.C.*, 527 U.S. 581, 588–92 (1999).

<sup>174</sup> See Mike DuBose & Blake DuBose, *Preventing Costly, Distracting Lawsuits*, MIKE DUBOSE, [http://www.mikedubose.com/posts/preventing\\_costly\\_distracting\\_lawsuits1/](http://www.mikedubose.com/posts/preventing_costly_distracting_lawsuits1/) (last visited Mar. 7, 2016) (explaining that litigation is often a lengthy process, spanning months to years); see also CROWELL & MORING, *THE ABCS OF CROSS-BORDER LITIGATION IN THE UNITED STATES* (2008), <https://www.crowell.com/files/abc-guide-to-cross-border-litigation.pdf> (“Litigation in the U.S. is often a slow . . . process . . . [and] can take many months or even years.”).

hindered affected individuals.<sup>175</sup> As ASAN stated in its policy brief, “it has historically been difficult to enforce federal civil rights law within the area of medical decision-making.”<sup>176</sup> Many physicians therefore “presume that, given the subjective nature of clinical judgment regarding organ transplantation decisions, disability civil rights laws may not be relevant or applicable.”<sup>177</sup> For this reason, individuals and families may not be able to bring an effective suit to enforce their rights. An individual may also not have the resources to litigate, as the process of bringing suit to court is time-consuming, expensive, and stressful.<sup>178</sup> These challenges have led to a lack of case law pertaining to organ transplantation discrimination on the basis of cognitive disability. Courts who do hear these cases, however, should implement clear guidelines for physicians that allow for discretion but also protect the rights of the disabled.

*B. Federally Implemented Amendments to the ASAN Framework*

Congress can also respond to this issue by amending or supplementing the current federal statutes to provide more guidance to physicians dealing with organ transplantation. In doing so, legislators should consider adopting ASAN’s policy framework.<sup>179</sup> New Jersey and Maryland have already adopted the ASAN framework, demonstrating the feasibility of this option.<sup>180</sup> While Congress enacted federal statutes such as Section 504 and Title II to eliminate discrimination on the basis of disability, these statutes did not provide sufficient guidance for doctors, regardless of how clear congressional intent may be. ASAN’s framework can provide

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<sup>175</sup> NE’EMAN ET AL., *supra* note 79, at 1.

<sup>176</sup> *Id.*

<sup>177</sup> *Id.* at 5.

<sup>178</sup> See Bruce Robins, *Litigation is Too Darn Expensive*, LAWYERS.COM (June 14, 2012), <http://research.lawyers.com/blogs/archives/21377-litigation-is-too-darn-expensive.html>.

<sup>179</sup> See NE’EMAN ET AL., *supra* note 79, at 7–9 (describing a summarization of the ASAN policy framework proposal).

<sup>180</sup> See *ASAN Antidiscrimination Bill*, *supra* note 16; see Crane, *supra* note 141.

further guidance that will clarify what physicians may do while exercising their discretion.

As discussed in Section V.A, it is difficult to raise legal claims for individuals who have been discriminated against on the basis of their cognitive disability, even under the protections of Section 504 and Title II.<sup>181</sup> Also, while these statutes seek to protect individuals with disabilities, there is difficulty in enforcing these statutes.<sup>182</sup> Healthcare providers, including transplant centers and physicians, “are already prohibited from discriminating on the basis of disability on the grounds of both” Section 504 and Title II.<sup>183</sup> These statutes, however, fail to define precisely what constitutes “discrimination” in the context of organ transplantation.<sup>184</sup> Certain proactive measures, such as ASAN’s policy proposal, can therefore be taken to combat this uncertainty and provide better protection for the disabled. Adopting a policy similar to ASAN’s framework would allow for states to act proactively in regards to passing non-discrimination legislation for organ transplantation, rather than acting reactively as seen with California, New Jersey, and Pennsylvania.<sup>185</sup>

First, the agencies responsible for oversight of transplant centers and physicians, such as the U.S. Department of Health and Human Services’ OCR, should require that the head of each transplant center has a designated responsibility. This person should be required to hold seminars to fully inform their transplant teams of the federal civil rights laws and the level of conduct at which they are obligated to perform. Moreover, this designated physician should be required to conduct semi-annual employee evaluations and report the results of those evaluations to OCR at least four times per year.

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<sup>181</sup> See *supra* Section V.A.

<sup>182</sup> See *The ADA and City Government Problems*, U.S. DEP’T JUST. (Oct. 9, 2008), <http://www.ada.gov/comprob.htm> (“When self-evaluations are not conducted and transition plans not developed, city governments are ill-equipped to implement accessibility changes required by the ADA.”); see also NE’EMAN ET AL., *supra* note 79, at 5; see also *supra* Part III.

<sup>183</sup> NE’EMAN ET AL., *supra* note 79, at 5.

<sup>184</sup> See *id.*

<sup>185</sup> See *supra* Part III.



Any legislation passed should also, like California, explicitly clarify what legal protections are provided against discrimination for individuals with cognitive disabilities.<sup>186</sup> In doing so, legislation would explicitly prohibit discrimination on the basis of cognitive disabilities unless a physician can articulate medically relevant reasons for prohibition on a case-by-case basis.<sup>187</sup> The Department of Health and Human Services should also issue guidance to physicians in this field to “explicitly clarify[] the applicability of [Title II] and Section 504 to organ transplantation settings, indicating examples of acceptable and unacceptable criteria for evaluation and clarifying that non-medically relevant conditions” cannot be considered in the decision process.<sup>188</sup>

Ultimately, a national legislative framework would provide the most effective means of protecting those with cognitive disabilities who seek organ transplants. Although self-imposed regulations may address some instances of discrimination, they would not be a uniform solution and may not be effectively implemented and enforced.<sup>189</sup> Furthermore, it would be more effective to address this issue proactively rather than to wait and hope for self-imposed regulations.<sup>190</sup> National standards could also impose external penalties for non-compliance. These deterring effects can include required reports to the head of transplant teams or departments in facilities and mandated annual or bi-annual reports to the U.S. Department of Health and Human Services regarding the reviews and audits that they have conducted.<sup>191</sup> Non-compliance would also

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<sup>186</sup> NE’EMAN ET AL., *supra* note 79, at 7.

<sup>187</sup> See CAL. HEALTH & SAFETY CODE § 7151.35(a) (2015); see also NE’EMAN ET AL., *supra* note 79, at 7.

<sup>188</sup> NE’EMAN ET AL., *supra* note 79, at 8.

<sup>189</sup> Self-imposed or voluntary rules and regulations are highly unrealistic because health centers lack incentive to change current procedures.

<sup>190</sup> Proactive measures will help prevent discrimination on the basis of cognitive disability. Moreover, although not demonstrated in California and New Jersey, reactive measures can be detrimental on the individual in dire need of a transplant. See Frank, *supra* note 123, at 111–15.

<sup>191</sup> This proposed solution does not suggest supplanting current internal reviews conducted by hospitals.

continue to subject the transplant center decreases in federal funding.<sup>192</sup>

In addition to ASAN's framework, there should be further guidance as to what constitutes "discrimination." ASAN does not take into account rare diseases, like CSS, unfamiliar to research experts and physicians. In these cases, the determination that the conditions cause medical complications post-transplant may not be conclusive. To address this, guidelines should provide further instructions on what the evaluating physician must do; for example, the physician could either have to contact specialists globally or report to a consulting doctor in the facility.<sup>193</sup> Until physicians can find an affirmative contraindication<sup>194</sup> between that specific intellectual disability and the transplant process, they should not be allowed to preclude the intellectually disabled individual from eligibility on the transplant waitlist.

Narrower and stricter guidelines supplementing ASAN's framework should include a spectrum of risk classification. The transplant team and evaluating physicians should be given proper instructions on how to evaluate an individual's risk for medical complications post-transplantation by assessing several different factors. After careful consideration, physicians should place the individual in one of three categories: Low-Risk, Moderate-Risk, and

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<sup>192</sup> This is an ordinary penalty that the U.S. Department of Health and Human Services would impose as a result of violation. See *Resolution Agreements*, *supra* note 25.

<sup>193</sup> For example, Maverick's doctors provided his parents with information about CSS and Maverick's mother contacted a doctor cited in the materials to inquire if children with CSS have compromised immune systems. *Cohen*, *supra* note 1. Dr. Gijs Santen replied that "[t]here is no objective problem with the immune system (in children with [CSS]) . . . It is difficult to use infection risk as a reason not to perform a heart transplant." *Id.* In Maverick's case, his physicians should have proactively contacted Dr. Santen, rather than placing that burden on Maverick's parents.

<sup>194</sup> This medical term refers to "a specific situation in which a drug, procedure, or surgery should not be used because it may be harmful to the person." *Contraindication*, MEDLINEPLUS, <https://www.nlm.nih.gov/medlineplus/ency/article/002314.htm> (last visited Mar. 7, 2016).

High-Risk.<sup>195</sup> A “Low-Risk” individual would be at normal risk post-transplant operation and they should be proceeded to be placed on the national transplant waiting list. “Moderate-Risk” individuals would have some risk of medical complications slightly higher than normal post-transplant operation. This classification, however, would not preclude eligibility. In these cases, physicians should be required to reach out to experts and other researchers to verify whether or not that particular intellectual disability contraindicates organ transplantation. “High-Risk” individuals would be those whose intellectual disability results in a medically confirmed increased risk of complication. These individuals should be precluded from being listed as a transplant candidate. Such a system of classification would protect the rights of those with cognitive disabilities while preventing those transplants that the medical community has deemed problematic.

### *C. Physician Disclosure of Reason for Preclusion*

In addition to imposing legislation similar to ASAN’s framework on organ transplant centers, these transplant centers should be required to fully inform their physicians and transplant teams of civil rights laws and guidelines. Furthermore, if physicians preclude an individual from receiving an organ transplant due to their cognitive disabilities, they should intelligently and fully disclose the reasons to the patients. These disclosures should be given both orally as well as in written form to encourage compliance. This practice may deter physicians from giving false evaluations<sup>196</sup> rooted in the mentality that providing a transplant to a disabled patient in effect “wastes” the organ. This requirement deters such conduct because after a formal denial, if a patient investigates the denial and uncovers discriminatory practices, he can pursue litigation. Oral and written disclosures of the reasons for

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<sup>195</sup> Similar proposed classification systems have suggested that physicians categorize “children with intellectual disabilities seeking transplant[ation].” See Frank, *supra* note 123, at 124–25.

<sup>196</sup> This Note does not suggest that false evaluations are malicious or intentional, but instead may be the product of human error. Implementing these deterring factors may further encourage careful practice.

transplant denial may provide patients with more tangible evidence to support their legal claims.

#### CONCLUSION

There is great disparity in the supply and demand for organs, and as a result, physicians must inevitably prioritize some transplant applicants over others. Physicians must balance maximizing the benefit of scarce organs with maintaining their ethical duty of creating equal access to transplantation. Whether or not an individual has an intellectual disability, he or she should be given as fair a chance at life as any other individual. Physicians should not hastily deem intellectually disabled individuals as incapable of surviving post-transplantation operations due to associated medical complications, given that cognitive disabilities do not necessarily cause those complications.

Clinical judgment in regards to organ transplantation decisions entail subjectivity while Section 504 and Title II do not explicitly address the issue of organ transplantation. As a result, many transplant physicians presume that Section 504 and Title II are not applicable to organ transplant eligibility determinations or may not realize that the term “disability” extends to cognitive disability.<sup>197</sup> To counter this, there should be government involvement through implementation of regulations supplementing Section 504 and Title II. This supplemental regulation should include specific guidelines instructing physicians on how to approach situations concerning individuals with cognitive disabilities and deterring physicians from proceeding in a discriminatory manner. Though reliance on physician expertise still remains the focal point of the evaluation, these guidelines provide needed protection from discrimination for individuals with cognitive disabilities. These protections will also allow for the individuals who feel that they have been discriminated against the proper means to seek court intervention.

Adopting a similar framework to ASAN’s, as well as some stricter guidelines, would ease the process of candidacy for allocating and procuring organs for transplant. Maverick, and others with cognitive disabilities, deserves an opportunity to live and

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<sup>197</sup> NE’EMAN ET AL., *supra* note 79, at 5.

thrive. He should have the same access to proper resources and his physicians should be required to conduct extensive research before refusing access to the transplant waitlist. These proposed guidelines would afford Maverick's parents access to concrete evidence to file suit and a chance at gaining some sort of remedy for their alleged discrimination. These suggested approaches can create an equitable platform for individuals with cognitive disabilities for transplant eligibility.