

# The Heart of the Discrimination Problem: Insufficient State Protection for People with Intellectual and Developmental Disabilities In the Organ Transplant Process

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*ABSTRACT: People with intellectual and developmental disabilities continue to face discrimination in the organ transplant process despite federal laws prohibiting such discrimination. Some states have passed legislation specifically prohibiting discrimination against people with disabilities in all aspects of the organ transplant process. However, such laws are not yet effective in practice. States' adoption of laws prohibiting such discrimination is a step in the right direction. The current laws stand merely as a symbolic gesture rather than as a genuine shield against discrimination. This Note identifies the shortcomings of current state statutes and makes recommendations on how to improve future and current state statutes.*

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## I. INTRODUCTION

Imagine a young woman with a terminal heart condition. She is referred by her doctor for a combined heart and kidney transplant that could save her life. Her insurance approves the procedure but requires her surgery to be performed in-state, where only two transplant centers operate. Yet, both hospitals refuse to approve her transplant based on the fact that she is categorized as belonging to a particular group of people. The first hospital refused to even meet or examine her and categorically deemed all people like her ineligible for a transplant. The second also refused, reasoning that people like her could not follow the necessary protocols after the surgery. If you found out this woman was denied because she was Black, you would likely say this is completely unacceptable. If you learned this woman was denied because she was a member of the LGBTQIA+ community, you would likely be just as horrified. What if you discovered that this woman was denied a lifesaving procedure because she had a developmental disability?

Unfortunately, this was the all too true story of Sandra Jensen, a young woman with Down syndrome living in California in 1995.<sup>1</sup> Sandra was mostly independent and had achieved some remarkable feats by that point in her life: “She lived in her own apartment, handled her own money and cooked her own meals. She also co-founded two disability advocacy organizations and served on a state task force. She mobilized supporters who launched a public campaign and got [Disability Rights California] to help.”<sup>2</sup> Nevertheless, the

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1. See *Sandra Jensen Needed a Heart-Lung Transplant, but Several Hospitals Did Not Believe a Woman with Down Syndrome Was a Good Candidate for Surgery*, DISABILITY RIGHTS CAL. (July 25, 2018), <https://www.disabilityrightsca.org/stories/sandra-jensen-needed-a-heart-lung-transplant-but-several-hospitals-did-not-believe-a-woman> [https://perma.cc/JSG9-AVG9].

2. See *id.*

organ transplant centers did not see her for her specific capabilities nor did they factor in that “there was no evidence indicating that her disability lessened the likelihood of the transplant being successful.”<sup>3</sup> The centers treated Sandra not as a person living *with* a disability, but as *only* her disability.<sup>4</sup>

Sandra’s story is not an isolated event. Even more than 25 years later, people with intellectual and developmental disabilities (“I/DD”)<sup>5</sup> frequently face discrimination when it comes to the often lifesaving organ transplant process.<sup>6</sup> Although federal laws exist—the American with Disabilities Act of 1990 (“ADA”) and Section 504 of the Rehabilitation Act of 1973 (“Section 504”)—that prohibit discrimination against people with I/DD, these laws fall short from providing substantial protection in practice, including in the organ transplant process.<sup>7</sup> While some states have passed legislation specifically prohibiting discrimination against people with disabilities in the organ transplant context,<sup>8</sup> this discrimination still often occurs even in those states.<sup>9</sup>

3. NAT’L COUNCIL ON DISABILITY, ORGAN TRANSPLANT DISCRIMINATION AGAINST PEOPLE WITH DISABILITIES 59 (2019), [https://ncd.gov/sites/default/files/NCD\\_Organ\\_Transplant\\_508.pdf](https://ncd.gov/sites/default/files/NCD_Organ_Transplant_508.pdf) [<https://perma.cc/5LMG-ERLG>].

4. Sandra repeatedly asked to be “treat[ed] . . . like an individual, not like a member of a particular group.” Angela T. Whitehead, *Rejecting Organs: The Organ Allocation Process and the Americans with Disabilities Act*, 24 AM. J.L. & MED. 481, 497 (1998).

5. One source describes I/DD as follows:

Intellectual and Developmental disabilities refer to two disability groupings. ‘Developmental disability’ is the broader, umbrella term and includes (but is not limited to) ‘Intellectual disability.’ **Developmental disabilities (DD)** are a group of conditions due to a delay or impairment in cognitive ability, physical functioning, or both. . . . **Intellectual disability (ID)** is the most common developmental disability. Children and adults with an ID have significant difficulties in both intellectual functioning (communicating, learning, problem solving) and adaptive behavior (everyday social skills, routines, hygiene).

*What Exactly Do We Mean by IDD?*, ACL BOULDER (Mar. 12, 2019), <https://www.aclboulder.org/blog/2019/3/12/so-what-do-we-mean-by-idd> [<https://perma.cc/B7PQ-K37B>].

6. NAT’L COUNCIL ON DISABILITY, *supra* note 3, at 21; Ari Ne’eman, Steven Kapp & Caroline Narby, *Organ Transplantation and People with I/DD: A Review of Research, Policy and Next Steps*, AUTISTIC SELF ADVOC. NETWORK 2–4 (Mar. 2013), [https://autisticadvocacy.org/wp-content/uploads/2013/03/ASAN-Organ-Transplantation-Policy-Brief\\_3.18.13.pdf](https://autisticadvocacy.org/wp-content/uploads/2013/03/ASAN-Organ-Transplantation-Policy-Brief_3.18.13.pdf) [<https://perma.cc/HBA9-UETY>] (listing statistics supporting discrimination against people with intellectual and developmental disabilities in access to organ transplant).

7. See Laura C. Hoffman, *Access to Health Care and the Intellectually and Developmentally Disabled: Anti-Discrimination Law, Health Law, and Quality of Life*, 22 J. GENDER, RACE & JUST. 151, 165 (2019) (citing Tien-Kha Tran, Note, *Organ Transplantation Eligibility: Discrimination on the Basis of Cognitive Disability*, 24 J.L. & POL’Y 631, 635, 643 (2016)).

8. *Nondiscrimination in Organ Transplantation Laws & Toolkit*, NAT’L DOWN SYNDROME SOC’Y, <https://www.ndss.org/programs/ndss-legislative-agenda/healthcare-research/nondiscrimination-in-organ-transplantation-laws-toolkit> [<https://perma.cc/69M2-A7ZC>].

9. NAT’L COUNCIL ON DISABILITY, *supra* note 3, at 54 (“This existence of an underlying bias against people with disabilities is apparent on the websites of many organ transplant centers, even in states with their own antidiscrimination laws.”).

This Note analyzes the shortcomings of the state laws currently in existence. State statutes prohibiting discrimination against people with disabilities are a big step forward in protecting people with I/DD in the organ transplant process. Nevertheless, current state statutes are not effective. Furthermore, not all states have passed this type of legislation. This Note attempts to guide states as to which provisions they should include to provide sufficient protection to individuals with I/DD. These recommendations are aimed at both states that have not yet passed such legislation as well as states that have passed such legislation to strengthen their current statutes through amendments.

## II. DISCRIMINATION IN THE ORGAN TRANSPLANT PROCESS

Discrimination against people with I/DD in the organ transplant process has a complex existence. Sections A, B, and C, respectively, will describe the history of discrimination in the organ transplant process, the opportunities for discrimination throughout the organ transplant process, and the unsupported bias that underlies this discrimination.

### A. NOTABLE CASES OF DISCRIMINATION IN THE ORGAN TRANSPLANT PROCESS

People with I/DD have faced, and continue to face, discrimination in the organ transplant process.<sup>10</sup> Such discrimination comes in both obvious and subtle forms, and therefore can sometimes be difficult to recognize as discrimination.<sup>11</sup> This Section will introduce three people who have faced discrimination in the organ transplant process.

In the case of Sandra, the first person with Down syndrome to receive a transplant, Stanford Hospital denied her a transplant without even meeting or examining her, demonstrating an explicit form of discrimination.<sup>12</sup> Stanford simply concluded “that people with Down Syndrome were considered *categorically* inappropriate for heart/lung transplants.”<sup>13</sup> Such a blatant form of discrimination often rests on the determination that people with I/DD are *unworthy* of an organ transplant.<sup>14</sup> This perspective is all too prevalent today. The second hospital Sandra visited, U.C. San Diego Medical Center, “conclud[ed] that her condition made her unable to follow the complex post-transplantation medical regimen that would be required of

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10. Ne’eman et al., *supra* note 6, at 1–2.

11. See NAT’L COUNCIL ON DISABILITY, *supra* note 3, at 28 (describing discrimination in the initial stages of the organ transplant process both explicitly by failing to recommend a transplant altogether or implicitly by misdiagnosing the issue related to the disability).

12. See Ne’eman et al., *supra* note 6, at 1–2; see also NAT’L COUNCIL ON DISABILITY, *supra* note 3, at 59 (describing Sandra’s case and discussing California’s transplant nondiscrimination law).

13. Ne’eman et al., *supra* note 6, at 1 (emphasis added) (footnote omitted).

14. *Id.* at 2.

her.”<sup>15</sup> This sort of denial demonstrates a more subtle form of discrimination that people with I/DD often face throughout the organ transplant process: assumptions about them based solely on the fact that they have a disability.<sup>16</sup> Such “unfounded assumptions [often include] that a person’s disability may make him or her less able to comply with postoperative requirements, or that having a disability lowers the quality . . . of a person’s life.”<sup>17</sup>

Sandra’s story exemplifies that people with I/DD must often fight an uphill battle to receive an organ transplant. Sandra eventually did receive the heart and lung transplant from Stanford.<sup>18</sup> The hospital finally reversed its decision, but only after dealing with the unrelenting national pressure Sandra’s case ignited.<sup>19</sup> Although an ultimate success for Sandra, her story as “the first person with Down syndrome to receive a major [organ] transplant”<sup>20</sup> brought attention to the unequal treatment in the organ transplant process.<sup>21</sup>

Media attention continues to be the primary means of fighting this type of discrimination for someone with I/DD who is denied an organ transplant.<sup>22</sup> This is far from a practical or sustainable method of enacting equality. Not all people who face discrimination in the organ transplant process have the means or knowledge to create national awareness on their specific case.<sup>23</sup> Currently, the American legal system leaves people with I/DD vulnerable to be categorically excluded from life-saving procedures by not providing adequate protection against discrimination.

The most noteworthy case to follow Sandra’s was that of Amelia Rivera,<sup>24</sup> a little girl with Wolf-Hirschhorn syndrome.<sup>25</sup> In 2012, her parents took her to Children’s Hospital of Philadelphia, where she was denied a kidney transplant because of her intellectual disability.<sup>26</sup> Unlike Sandra, Amelia did not need to be placed on the transplant waitlist since one of her family

15. *Id.* at 1 (footnote omitted); *see also* NAT’L COUNCIL ON DISABILITY, *supra* note 3, at 59 (describing Sandra’s case and discussing California’s transplant nondiscrimination law).

16. NAT’L COUNCIL ON DISABILITY, *supra* note 3, at 12–13, 65.

17. *Id.* at 48.

18. DISABILITY RTS. CAL., *supra* note 1.

19. Ne’eman et al., *supra* note 6, at 2.

20. DISABILITY RTS. CAL., *supra* note 1.

21. *Id.*

22. *See* NAT’L COUNCIL ON DISABILITY, *supra* note 3, at 57–58, 61–63 (recounting the stories of Amelia Rivera, Lief O’Neill, and Paul Corby).

23. *See id.* at 50 (“[P]eople with disabilities who are denied organ transplants may not realize that they have been subjected to illegal discrimination . . .”).

24. CRivera75, *Brick Walls*, WOLFHIRSCHHORN.ORG (Jan. 12, 2012), <http://wolfhirschhorn.org/2012/01/amelia/brick-walls> [<https://perma.cc/KJK4-KFC3>].

25. Wolf-Hirschhorn syndrome is a genetic condition that can cause “severe developmental delays, a characteristic facial appearance, and . . . a variety of other birth defects.” *Wolf-Hirschhorn Syndrome*, WOLFHIRSCHHORN.ORG, <http://wolfhirschhorn.org/about-wolf-hirschhorn-syndrome> [<https://perma.cc/V5GH-HYZX>].

26. NAT’L COUNCIL ON DISABILITY, *supra* note 3, at 57–58.

members had volunteered to donate the kidney.<sup>27</sup> Nonetheless, the hospital refused to conduct the procedure without even attempting to evaluate her individual suitability for the transplant.<sup>28</sup> Her mother recounted her conversation with the doctor in a blog post that sparked national fury:

“So you mean to tell me that as a doctor, you are not recommending the transplant, and when her kidneys fail in six months to a year, you want me to let her die because she is mentally retarded? There is no other medical reason for her not to have this transplant other than she is **MENTALLY RETARDED!**” [The doctor replied,] “[y]es. This is hard for me, you know.”<sup>29</sup>

After her story created a media frenzy, Children’s Hospital of Philadelphia came forward, reconsidered, and eventually approved Amelia’s transplant.<sup>30</sup>

Although some people with I/DD are fortunate enough to receive organ transplants, this ‘national-outcry-approach’ does not always work, as illuminated by the case of Paul Corby.<sup>31</sup> Paul, an adult with autism and psychiatric disabilities, was denied a heart transplant due to “his perceived inability to” follow post-transplant care “because he was carrying a doll for comfort and could not name all nineteen of the medications he took—a feat which would be quite difficult for many people.”<sup>32</sup> Despite the fact that his case was well-publicized, Paul has still not been approved for a transplant.<sup>33</sup> The disparity of success demonstrates “that an ad hoc approach to fighting discrimination against people with I/DD in organ transplantation remains insufficient.”<sup>34</sup> Although his mother contemplated bringing a lawsuit, she was

27. *Id.* at 30.

28. *Id.* (citing CRivera75, *supra* note 24).

29. CRivera75, *supra* note 24.

30. Ne’eman et al., *supra* note 6, at 4.

31. *See id.* (discussing Paul Corby’s inability to receive a transplant, despite media outcry).

32. NAT’L COUNCIL ON DISABILITY, *supra* note 3, at 61–62. “[T]he denial letter sent to his mother” specifically stated that “he was rejected because of his ‘psychiatric issues, autism, the complexity of the process . . . and the unknown and unpredictable effect of steroids on behavior.’” Lenny Bernstein, *People with Autism, Intellectual Disabilities Fight Bias in Transplants*, WASH. POST (Mar. 4, 2017), [https://www.washingtonpost.com/national/health-science/people-with-autism-intellectual-disabilities-fight-bias-in-transplants/2017/03/04/756ff5b8-feb2-11e6-8f41-ea6ed597e4ca\\_story.html](https://www.washingtonpost.com/national/health-science/people-with-autism-intellectual-disabilities-fight-bias-in-transplants/2017/03/04/756ff5b8-feb2-11e6-8f41-ea6ed597e4ca_story.html) [https://perma.cc/BZ45-YL6J]. This Note deliberately uses a combination of “identity-first” and “person-first” language. The author respects both language choices and chose to use both interchangeably depending on what made the sentence flow better and provided the clearest meaning.

33. *See* Bernstein, *supra* note 32. Additionally,

His mother reports that [Paul’s] condition is stable, but that because of previous rejections following evaluation, he does not wish to undergo any further evaluations unless he is guaranteed placement on the transplant recipient list. As a result, he and his family are not seeking further evaluations by transplant centers at this time.

NAT’L COUNCIL ON DISABILITY, *supra* note 3, at 62.

34. Ne’eman et al., *supra* note 6, at 4 (suggesting the ad hoc approach be replaced with “[a] systemic law and policy response.”).

advised that they would ultimately lose given the lack of regulations surrounding who may receive an organ transplant.<sup>35</sup>

B. *THE ORGAN TRANSPLANT PROCESS: OPPORTUNITIES FOR  
DISCRIMINATION*

The organ transplant process involves many stages and nuances, and as a result, discrimination against people with I/DD can take many different shapes.<sup>36</sup> The stories recounted in Section II.A of this Note mainly demonstrate discrimination at the evaluation stage—one of the four primary stages to receive an organ transplant.<sup>37</sup> To receive an organ transplant, a patient must go through each of the following:<sup>38</sup>

1. The patient's physician refers the patient to an organ transplant center.
2. The organ transplant center evaluates the patient's eligibility for an organ transplant.
3. If the organ transplant center determines that the patient is eligible, the organ transplant center places the patient on the national waiting list.
4. If a match is found, the transplant center carries out transplantation of that organ.<sup>39</sup>

People with I/DD seeking transplants can even be discriminated before the first stage of the organ transplant process. A physician may misdiagnose organ failure altogether by “mistak[ing] symptoms of organ failure for a psychological ailment or a more minor physical ailment” due to “disability-related stereotyping, prejudice, or unfamiliarity with people with a disability.”<sup>40</sup> This type of discrimination can be seen in the aforementioned case of Paul Corby,<sup>41</sup> where the many physicians who evaluated him initially considered his deteriorating physical condition may have been due to heart problems.<sup>42</sup> However, after learning Paul had autism, the physicians insisted Paul's worsening physical symptoms—chest pains, vomiting, persistent cough, inability to eat, and rapid heartbeat—were merely symptoms of anxiety and refused to test his heart.<sup>43</sup>

35. See Shira Stein, *Organ Transplant Disability Bias Gets Second Look Under Trump*, BLOOMBERG L. (Mar. 29, 2019, 4:30 AM), <https://news.bloomberglaw.com/health-law-and-business/organ-transplant-disability-bias-gets-second-look-under-trump> [<https://perma.cc/2976-UC4N>].

36. NAT'L COUNCIL ON DISABILITY, *supra* note 3, at 25 (describing the four steps in the organ transplant process). “As explained throughout this report, disability discrimination, particularly discrimination against people with psychiatric disabilities and people with I/DD, can be found at almost all stages of the organ transplantation process.” *Id.*

37. *See id.*

38. Stages three and four require very little discretion by the organ transplant centers. Therefore, this Note will not discuss discrimination at those stages.

39. NAT'L COUNCIL ON DISABILITY, *supra* note 3, at 25.

40. *Id.* at 28.

41. *See supra* Section II.A (discussing the story of Paul Corby).

42. NAT'L COUNCIL ON DISABILITY, *supra* note 4, at 29.

43. *See id.* at 28–29. Doctors continued to insist that it was anxiety for three months. *Id.*

A patient can often experience discrimination at the first stage in the transplant process, as a person's physician may refuse to make a referral for an evaluation based on their disability.<sup>44</sup> Yet, discrimination at this stage, while shocking, is not determinative in whether a person can successfully receive an organ transplant because a patient can often sidestep a physician's lack of cooperation by making a self-referral.<sup>45</sup> Nonetheless, without a physician referral it may take more time for a patient to receive an evaluation from a transplant center,<sup>46</sup> which can take an emotional and physical toll on a patient who is critically ill.<sup>47</sup> A 2004 survey demonstrated "that only 52 percent of people with disabilities who requested a referral to a specialist regarding an organ transplant evaluation actually received a referral, while 35 percent of those 'for whom a transplant had been suggested' never even received an evaluation."<sup>48</sup> Although no survey evaluates these statistics in the general population of individuals without I/DD, organ-specific studies suggest that people without I/DD receive a referral and a subsequent evaluation at much higher rates than people with I/DD.<sup>49</sup>

A patient may also experience discrimination between stages. Physicians may fail to recommend intermediate therapies or treatments that can extend a patient's life while waiting for a transplant to patients with I/DD "that they would recommend immediately to patients without disabilities."<sup>50</sup> Discrimination of this sort was exemplified in the case of Lief, an eleven-year-

44. Ne'eman et al., *supra* note 6, at 1.

45. UNITED NETWORK FOR ORGAN SHARING, WHAT EVERY PATIENT NEEDS TO KNOW 10 (2021), <https://unos.org/wp-content/uploads/unos/Brochure-113-What-every-patient-needs-to-know.pdf> [<https://perma.cc/HC4Z-LF9S>] ("You can also contact a transplant center yourself. A referral from a doctor is not necessary, but your doctor may have test results and medical history that will make it easier for the transplant center to start the evaluation process.").

46. *See id.* (implying that the process may be smoother with a physician's referral).

47. *See* NAT'L COUNCIL ON DISABILITY, *supra* note 3, at 50 (discussing how taking on a lengthy litigation may be difficult for I/DD transplant patients because of how critically ill they are and how little time and strength they may have).

48. *Id.* at 29 (citing MINN. DEP'T OF ADMIN.: GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES, LIVES WORTH SAVING: ORGAN TRANSPLANTATION AND PEOPLE WITH DISABILITIES 4 (2004), [https://mn.gov/mnddc/news/pdf/archive/transplant\\_article6-04.pdf](https://mn.gov/mnddc/news/pdf/archive/transplant_article6-04.pdf) [<https://perma.cc/7VZC-CURK>]).

49. *Id.* "One study examining patients with liver disease at a Veterans Affairs center between 2002 and 2003 found that, while many barriers to transplantation exist, of patients who received a referral, 75 percent received an evaluation." *Id.* (citing Venodhar R. Julapalli, Jennifer R. Kramer & Hashem B. El-Serag, *Evaluation for Liver Transplantation: Adherence to AASLD Referral Guidelines in a Large Veterans Affairs Center*, 11 LIVER TRANSPLANTATION 1370, 1372 fig.1 (2005)). "Another study found that between 92.1 and 95.5 percent of patients deemed appropriate for evaluation for kidney transplant received a referral and that of those, 81.4 percent were placed on the transplant waiting list." *Id.* (citing Arnold M. Epstein et al., *Racial Disparities in Access to Renal Transplantation—Clinically Appropriate or Due to Underuse or Overuse?*, 343 NEW ENG. J. MED. 1537, 1541 tbl.3 (2000)).

50. *Id.*

old boy with autism in need of a heart transplant.<sup>51</sup> Lief's medical team denied his heart transplant and also failed to inform his family that he could receive "a left ventricular assist device, or LVAD, [which] is considered a standard 'bridge therapy' on the way to receiving a transplanted heart."<sup>52</sup> Although there may be no direct proof that the doctors did not inform Lief about the option of receiving an LVAD because he was autistic, Lief's entire experience—from being denied a transplant from multiple centers to eventually receiving a transplant—demonstrates that he was treated differently than someone without I/DD.<sup>53</sup> As Lief's mother noted, after Stanford finally accepted him for a heart transplant, "she was told by the doctors that the transplant was unprecedented because they had never transplanted a heart into a child with autism as 'severely affected' as Lief," which she felt demonstrated that the doctors viewed him, and others like him, as less likely to receive a transplant.<sup>54</sup>

The second step in the process—the evaluation stage—which is critical to receiving an organ transplant, opens the door to many opportunities for discrimination against people with I/DD. After a person receives a referral or a self-referral to one of the 25<sup>255</sup> organ transplant centers in the country, a patient must then be evaluated by the organ transplant center before being accepted as a transplant candidate and subsequently placed on the organ transplant waitlist.<sup>56</sup> "The typical evaluation consists of various medical tests to determine current health status and evaluations of the patient's psychological health, financial situation, and social supports."<sup>57</sup> As in the case with Stanford's initial decision in denying Sandra, some transplant centers may categorically refuse to even evaluate a patient with I/DD as a candidate for a transplant.<sup>58</sup>

Every transplant center, though, uses their own process and criteria in the evaluation process.<sup>59</sup> Some transplant centers, and many individual

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51. *See id.*

52. *See id.*

53. A lack of direct evidence of discrimination is not uncommon, given "the informal manner in which organ transplant eligibility decisions are often made makes it difficult to determine whether discrimination occurred." *Id.* at 50. For example, "62 percent of pediatric transplant centers tend[] to make 'eligibility decisions based on disability . . . informally, making discrimination difficult to show.'" *Id.* at 30 (emphasis added) (quoting Rita Price, *Should a Disability Affect Who Gets Organ Transplants?*, COLUMBUS DISPATCH (Oct. 22, 2017, 5:26 AM), <https://www.dispatch.com/news/20171022/should-disability-affect-who-gets-organ-transplants> [<https://perma.cc/N9DT-NT28>]).

54. *See id.* at 62.

55. *Id.* at 28 (noting this number was accurate as of March 2019).

56. *See id.* at 25.

57. *Id.* (citing UNITED NETWORK FOR ORGAN SHARING, *supra* note 45, at 7).

58. *See id.* at 28.

59. *See id.* at 25 (citing *Before the Transplant*, UNITED NETWORK FOR ORGAN SHARING, <https://transplantliving.org/before-the-transplant> [<https://perma.cc/M5UG-G7B7>]).

physicians, view I/DD to be a relative or absolute contraindication—an indication that a patient is unsuitable for organ transplantation.<sup>60</sup> After evaluating the patient, the transplant team will then decide whether to accept the patient as a transplant candidate, influenced both by guidelines produced by experts in the field, specific to the organ required, and by the transplant center’s own policies.<sup>61</sup> However, the transplant team retains a significant amount of discretion when evaluating a patient’s transplant eligibility, especially as it relates to the psychological posttransplant portion of the evaluation.<sup>62</sup>

C. *THE ORIGIN OF THE DISCRIMINATION: UNSUPPORTED BIAS*

The amount of discretion throughout the transplant process can bring to light the bias towards people with I/DD. Research and statistics indicate that doctors and transplant centers hold a significant amount of bias toward people with I/DD in the organ transplant process, irrespective of whether or not a transplant center’s policies actually identify I/DD as contraindications.<sup>63</sup> A 1995 study revealed that “65 percent of second-year medical students viewed Down syndrome as a contraindication to heart transplant[s].”<sup>64</sup> A “2013 survey of liver transplant providers found that while most organ transplant centers did not consider psychiatric disability to be an absolute contraindication to transplant, they did rank it among the top three ‘most controversial’ characteristics of patients.”<sup>65</sup> Additionally, a 2006 survey identified that “60 percent of transplant centers hav[e] . . . reservations about giving a kidney to someone with a mild or moderate [I/DD].”<sup>66</sup> “A 2008

60. See *id.* at 30. This is “even more likely” in adult programs than pediatric ones. *Id.* at 77 n.61 (citing Jackie Fortiér, *People with Developmental Disabilities May Face Organ Transplant Bias*, NPR: STATEIMPACT OKLA. (Mar. 15, 2018, 5:00 AM), <https://stateimpact.npr.org/oklahoma/2018/03/15/people-with-developmental-disabilities-may-face-organ-transplant-bias> [<https://perma.cc/CD5P-V8FF>]).

61. *Id.* at 26.

62. These factors “include: inadequate social or family support, psychiatric disorders that may compromise post-transplant compliance to medication regimes, self-destructive behaviors such as smoking and drug use, and poor adherence to medical treatment.” Sara Frank, Note, *Eligibility Discrimination of the Intellectually Disabled in Pediatric Organ Transplantation*, 10 J. HEALTH & BIOMEDICAL L. 101, 118 (2014).

63. “While some organ transplant centers do not specifically mention psychiatric or developmental disabilities as relative or absolute contraindications to transplants, they list medical noncompliance among the contraindications to transplant, and do not indicate that the transplant center will consider—as required by federal law—any supports that the patient has or is eligible to receive.” NAT’L COUNCIL ON DISABILITY, *supra* note 3, at 54.

64. See *id.* at 31 (citing Marilee A. Martens, Linda Jones & Steven Reiss, *Organ Transplantation, Organ Donation, and Mental Retardation*, 10 PEDIATRIC TRANSPLANTATION 658, 659 (2006)).

65. *Id.* at 31. Although psychiatric disabilities are distinct from I/DD, many people with psychiatric disabilities often face the same discrimination as people with I/DD. *Id.*

66. *Id.* at 30 (citing Joseph Shapiro, *Disabled Woman Dies While Awaiting Second Chance at Kidney Transplant*, NPR (June 13, 2012, 11:13 AM), <https://www.npr.org/sections/health-shots/>

survey . . . found that 85 percent of . . . transplant centers consider[ed] neurodevelopment status as a factor in determin[ing] [a patient's] transplant eligibility at least some of the time . . ."<sup>67</sup> All of these statistics are to say that because physicians have a great deal of discretion in determining whether to accept a patient as an organ transplant candidate, such bias by medical professionals results in unequal treatment of people with I/DD in the transplant process.

The biases by medical professionals against people with I/DD stem from "assumptions [they make] about the patient's quality of life, lifespan, and post-transplant compliance."<sup>68</sup> An article, published by Dr. Savulescu in 2001, demonstrates how many medical professionals view people with I/DD as having a lower quality of life:

It is probably unlawful to place lower priority on children with Down's syndrome and other disabilities who need heart transplants. But is it unethical? . . . Whether disability such as Down's<sup>69</sup> syndrome should be considered relevant in allocating a scarce resource turns on how much the disability associated with it detracts from a good life.

Down's syndrome is associated with intellectual disability, infertility, reduced opportunities for independent living and employment, shorter life, and early onset Alzheimer's disease. These all make those lives worse.<sup>70</sup>

Furthermore, medical professionals often assume that someone with I/DD "will be unable to comply with post-transplant regimens, including medication and follow-up appointments."<sup>71</sup> These many assumptions often

2012/06/13/154914089/disabled-woman-dies-while-awaiting-second-chance-at-kidney-transplant [https://perma.cc/8X4H-MWPF]).

67. Ne'eman et al., *supra* note 6, at 3 (citing Christopher T. Richards, LaVera M. Crawley & David Magnus, *Use of Neurodevelopmental Delay in Pediatric Solid Organ Transplant Listing Decisions: Inconsistencies in Standards Across Major Pediatric Transplant Centers*, 7 PEDIATRIC TRANSPLANTATION 843, 843-50 (2009)).

68. NAT'L COUNCIL ON DISABILITY, *supra* note 3, at 31 (citing Aaron Wightman, Douglas Diekema & Aviva Goldberg, *Consideration of Children with Intellectual Disability as Candidates for Solid Organ Transplantation—A Practice in Evolution*, PEDIATRIC TRANSPLANTATION Feb. 2018 at 1-3).

69. Dr. Savulescu uses the terminology "Down's syndrome," which is common in the United Kingdom. See, e.g., *About Down's Syndrome*, DOWN'S SYNDROME ASS'N., <https://www.downs-syndrome.org.uk/about-downs-syndrome> [https://perma.cc/663T-Q8AQ]. This Note uses "Down syndrome," which is "the preferred usage in the United States." NAT'L DOWN SYNDROME SOC'Y, NDSS PREFERRED LANGUAGE GUIDE 1 (2020), <https://www.ndss.org/wp-content/uploads/2020/09/NDSS-Preferred-Language-Guide-2020-2.pdf> [https://perma.cc/6QHC-SJGT].

70. Julian Savulescu, *Resources, Down's Syndrome, and Cardiac Surgery: Do We Really Want "Equality of Access"?*, 322 BRIT. MED. J. 875, 876 (2001).

71. NAT'L COUNC. ON DISABILITY, *supra* note 3, at 31.

cloud a physician's decision and hinder their ability to see a person with a disability as an individual with differing capabilities and support systems.<sup>72</sup>

These implicit biases toward people with I/DD in the organ transplant process are, for the most part, scientifically and statistically unfounded.<sup>73</sup> In a study of 42 kidney transplant patients with intellectual disabilities, patients' transplants were at least as successful, and in some cases more successful, than kidney transplants in patients without intellectual disabilities.<sup>74</sup> Likewise, a 2016 found that the survival rates of children with I/DD who received a liver transplant were comparable to children who did not have I/DD.<sup>75</sup> Quite a few other studies exist demonstrating similar outcomes. In 2010, the American Journal of Transplantation stated that "there is no scientific evidence or compelling data suggesting that patients with [I/DD]<sup>76</sup> should not have access to organ transplantation."<sup>77</sup> Furthermore, although some people with I/DD may have a more difficult time following post-operative procedures, "[p]atients with disabilities who receive proper supportive services that take into account their specific needs and disabilities . . . are perfectly capable of following complex postoperative care regimens."<sup>78</sup> People with I/DD are just as successful in receiving these transplants, so bias against them trying to prohibit their access is unfounded.<sup>79</sup>

72. See *id.* at 25–35.

73. See *id.* at 38–39 (discussing "studies [that] consistently find that transplant outcomes for people with disabilities are no worse than transplant outcomes for people without disabilities"); see also *id.* at 39 (finding that the only issue for specific forms of I/DD with transplant is some issues post-transplant because they "tend to have weaker immune systems").

74. *Id.* at 80 n.122 (citing Joseph Shapiro, *Dispute over Mental Competency Blocks Transplant*, NPR (Dec. 22, 2006, 3:28 PM), <https://www.npr.org/templates/story/story.php?storyId=6665577> [<https://perma.cc/9XN7-EPFY>]). Another "study followed 25 kidney transplant patients with intellectual disabilities and found all patients' grafts survived in the short term and concluded that disability is not a contraindication of kidney transplant." *Id.* (citing Toshiyuki Ohta et al., *Kidney Transplantation in Pediatric Recipients with Mental Retardation: Clinical Results of a Multicenter Experience in Japan*, 47 AM. J. KIDNEY DISEASES 518, 518–27 (2006)).

75. NAT'L COUNCIL ON DISABILITY, *supra* note 3, at 39 (citing Aaron Wightman, Evelyn Hsu, Qianqian Zhao & Jodi Smith, *Prevalence and Outcomes of Liver Transplantation in Children with Intellectual Disability*, 62 J. PEDIATRIC GASTROENTEROLOGY NUTRITION 808, 808–12 (2016)).

76. The original quote used the term "MR" to refer to "mental retardation," a term that has since been replaced with the more politically correct term I/DD. NAT'L DOWN SYNDROME SOC'Y, *supra* note 69, at 1.

77. Ne'eman, et al., *supra* note 6, at 3 (footnote omitted) (quoting N. Panocchia, M. Bossola & G. Vivanti, *Transplantation and Mental Retardation: What Is the Meaning of a Discrimination?*, 10 AM. J. TRANSPLANTATION 727, 729 (2010)).

78. NAT'L COUNCIL ON DISABILITY, *supra* note 3, at 40 (citing Ne'eman et al., *supra* note 6, at 4).

79. *Id.* at 39 ("[D]enying all patients with Down syndrome organ transplants on the basis of their disability ignores individual differences between patients and possible risk mitigation strategies, and discriminates on the basis of disability in violation of federal law.").

### III. OVERVIEW AND ANALYSIS OF CURRENT LAWS OFFERING PROTECTION AGAINST DISCRIMINATION IN THE ORGAN TRANSPLANT PROCESS

Federal laws and some state laws currently prohibit discrimination against people with disabilities in the organ transplant process. The ADA and Section 504, although not specific to the organ transplant process, prohibit discrimination against people with disabilities.<sup>80</sup> Additionally, a federal bill<sup>81</sup>—the Charlotte Woodward Organ Transplant Discrimination Prevention Act (“the Charlotte Act”)<sup>82</sup>—has been introduced specifically prohibiting discrimination against people with mental and physical disabilities in the organ transplant process.<sup>83</sup> Some states have started to do the same.<sup>84</sup> Nonetheless, neither federal laws nor the new state laws sufficiently protect people with disabilities facing discrimination in the organ transplant process. Since state laws have been growing and have the most chance of being passed, this Note will go on to discuss what can be done to fix these issues, specifically with state laws.

#### A. FEDERAL LAWS

There are no published cases to date at either the state or federal level that have been brought under federal law<sup>85</sup> or state law addressing discrimination against people with I/DD in the organ transplant process. One possible reason for this is that people with I/DD, and their families, who are denied an organ transplant may have a difficult time recognizing when they are being discriminated against based on their disability,<sup>86</sup> or may not know that their rights are being violated.<sup>87</sup> Additionally, the lack of federal guidance as to what actions constitute discrimination in the organ transplant process makes it difficult to recognize and prove discrimination.<sup>88</sup> Further, “the length of time it takes to pursue [these] discrimination claims under federal

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80. See *infra* Section III.A.

81. This bill was not yet passed as of Summer 2021. *H.R. 1235—Charlotte Woodward Organ Transplant Discrimination Prevention Act*, CONGRESS.GOV, <https://www.congress.gov/bill/117th-congress/house-bill/1235> [<https://perma.cc/3QCW-G4KJ>] (noting the most recent action occurred when the bill was “[r]eferred to the Subcommittee on Health” on February 24, 2021).

82. See NAT’L DOWN SYNDROME SOC’Y, *supra* note 8 (“The bill is named for Charlotte Woodward, an advocate with Down syndrome and member of the NDSS staff who received a life-saving heart transplant nearly nine years ago. Since then, she has advocated tirelessly to ensure others with Down syndrome and other disabilities have the same access to transplants.”). *Id.*

83. H.R. 1235, 117th Cong. (2021).

84. See *infra* Section III.B.

85. NAT’L COUNCIL ON DISABILITY, *supra* note 3, at 49. The author of this Note was also unable to find any cases to date.

86. *Id.* at 50 (“[T]he informal manner in which organ transplant eligibility decisions are often made makes it difficult to determine whether discrimination occurred.”).

87. *Id.*

88. *Id.*

law” deters victims of discrimination from pursuing a claim.<sup>89</sup> Patients, and their families, are usually fighting against the clock to stay alive and do not have the time to bring a suit to have the transplant center’s decision reversed.<sup>90</sup>

The ADA prohibits discrimination on the basis of disability, including in the organ transplant process. Congress passed the ADA in order to guarantee that people with disabilities have the same opportunities as those without disabilities by providing clear and enforceable standards.<sup>91</sup> Public hospitals and transplant centers are covered by Title II of the ADA, which provides that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any public entity.”<sup>92</sup>

Privately owned transplant centers are similarly covered by Title III of the ADA, as they are “public accommodations.”<sup>93</sup> Title III of the ADA precludes private transplant centers from “the imposition or application of eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities from fully and equally enjoying any goods, services, facilities, privileges, advantages, or accommodations.”<sup>94</sup> Furthermore, “[t]he ADA requires that organ transplant centers make reasonable modifications to their policies, practices, and procedures to ensure equal opportunity for people with disabilities<sup>95</sup> . . . [u]nless [those modifications] would cause a fundamental alteration of the transplant center’s services.”<sup>96</sup>

Section 504 provides similar protection as the ADA, with the same goal of affording people with disabilities the same opportunities as those without disabilities, although this statute applies more narrowly as it only applies to *federally funded* programs or organizations that provide healthcare.<sup>97</sup>

Although the ADA and Section 504 prohibit discrimination on the basis of I/DD in the organ transplant process, discrimination still occurs, often because both give insufficient guidance as to what actions actually constitute discrimination on the basis of disability in the organ transplant process.<sup>98</sup>

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89. *Id.*

90. *Id.*

91. 42 U.S.C. § 12101(b) (2018) (describing the purpose of the ADA).

92. 42 U.S.C. § 12132. “Public entity” is defined as “any State or local government [and] any department, agency, special purpose district, or other instrumentality of a State or States or local government.” 42 U.S.C. § 12131.

93. *See* 42 U.S.C. § 12181(7).

94. 42 U.S.C. § 12182(b)(2)(A)(i).

95. NAT’L COUNCIL ON DISABILITY, *supra* note 3, at 47 (citing 28 C.F.R. § 35.130(b)(7) (2008); 42 U.S.C. § 12182(b)(2)(A)(ii)).

96. *Id.* at 47 (citing 42 U.S.C. § 12182(b)(2)(A)(iii)).

97. *See* 29 U.S.C. § 794(a).

98. Ne’eman et al., *supra* note 6, at 5.

Many patients—and lawyers<sup>99</sup>—are not aware that these laws extend to the organ transplant process (and therefore patients do not end up bringing a claim).<sup>100</sup> Additionally, “[m]any clinicians presume that, given the subjective nature of clinical judgment regarding organ transplantation decisions, disability civil rights laws may not be relevant or applicable.”<sup>101</sup>

A new federal statute Congress is currently considering, the Charlotte Act, will not provide *enough* protection for people with a disability seeking an organ transplant, although it will be a critical step forward.<sup>102</sup> The Charlotte Act closely resembles many of the state statutes prohibiting such discrimination that this Note finds ineffective, but would be on a national scale.<sup>103</sup> Much like the ADA, Section 504, and current state statutes prohibiting discrimination, the Charlotte Act only advises physicians that they may not make certain decisions in the organ transplant process “solely on the basis of a qualified individual’s mental or physical disability.”<sup>104</sup> The Charlotte Act does not provide adequate guidance as to what that would mean in practice.<sup>105</sup> Ultimately, for many of the same reasons as current state statutes, the Charlotte Act would, if passed, fall flat in adequately protecting people with disabilities.

An important piece of federal legislation that fails entirely to take into account disabilities is the National Organ Transplant Act of 1984 (“NOTA”).<sup>106</sup> NOTA established the Organ Procurement and Transplant Network (“OPTN”), which is run by United Network for Organ Sharing (“UNOS”).<sup>107</sup> OPTN is overseen by the Department of Health and Human Services (“HHS”). UNOS/OPTN runs the national waitlist for organ transplant recipients, and has created the various medical and geographic criteria used in matching organs to recipients,<sup>108</sup> none of which takes into account a person’s disabilities.<sup>109</sup> Additionally, while UNOS/OPTN has created practice guidelines for medical professionals in evaluating whether a

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99. Karen Corby’s inability to find a lawyer to represent her demonstrates this difficulty. When she called the Justice Department, an attorney told her “there are no regulations governing who can receive an organ, so there’s no basis for a lawsuit.” Stein, *supra* note 35.

100. NAT’L COUNCIL ON DISABILITY, *supra* note 3, at 50.

101. Ne’eman et al., *supra* note 6, at 5.

102. See H.R. 1235, 117th Cong. (2021).

103. See *supra* Section III.C–D (describing why current state statutes are insufficient).

104. H.R. 1235, 117th Cong. § 4(a) (2021).

105. See *infra* Part III.D for a discussion on why statutes’ text must adequately hold physicians accountable in order to sufficiently protect people with I/DD in the organ transplant process.

106. NAT’L COUNCIL ON DISABILITY, *supra* note 3, at 11.

107. *Id.*

108. *Id.*

109. *Id.* at 27 (citing generally ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK, ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK (OPTN) POLICIES (2018), [https://optn.transplant.hrsa.gov/media/1200/optn\\_policies.pdf](https://optn.transplant.hrsa.gov/media/1200/optn_policies.pdf) [<https://perma.cc/2FQ2-76AS>]).

person should be accepted as an organ transplant recipient, those guidelines are not legally enforceable.<sup>110</sup>

### B. STATE LAWS

While these federal laws are important to understand, this Note focuses on the state level, due to the rapidly increasing number of states introducing legislation specifically prohibiting discrimination against people with disabilities in the organ transplant process. Twenty-nine states as of the summer of 2021 have passed legislation prohibiting such discrimination, most of them in the last two years: California (1996);<sup>111</sup> New Jersey (2013);<sup>112</sup> Maryland (2015);<sup>113</sup> Massachusetts (2016);<sup>114</sup> Oregon (2017);<sup>115</sup> Delaware (2017);<sup>116</sup> Kansas (2018);<sup>117</sup> Ohio (2018);<sup>118</sup> Pennsylvania (2018);<sup>119</sup> Washington (2019);<sup>120</sup> Louisiana (2019);<sup>121</sup> Indiana (2019);<sup>122</sup> Virginia (2020);<sup>123</sup> Iowa (2020);<sup>124</sup> Missouri (2020);<sup>125</sup> Florida (2020);<sup>126</sup> Arkansas (2021);<sup>127</sup> Oklahoma (2021);<sup>128</sup> Wyoming (2021);<sup>129</sup> Nevada (2021);<sup>130</sup> Minnesota (2021);<sup>131</sup> Tennessee (2021);<sup>132</sup> Texas (2021);<sup>133</sup> Montana

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110. See NAT'L COUNCIL ON DISABILITY, *supra* note 3, at 45. UNOS/OPTN is also responsible for overseeing the organ transplant centers across the country. *Id.* at 12. Each transplant center is required by law to report the criteria and guidelines they use in determining whether to accept a person as a transplant candidate. *Id.* at 25. Once the transplant center accepts a patient as a transplant candidate, the patient is put on UNOS/OPTN's national organ waitlist. *Id.* at 12.

111. CAL. HEALTH & SAFETY CODE § 7151.35 (West 2021).

112. N.J. REV. STAT. §§ 26:6-86.1-6-86.2 (2021).

113. MD. CODE ANN., HEALTH-GEN. §§ 20-1601-1605 (West 2021).

114. MASS. GEN. LAWS ch. 111, § 236 (2021).

115. OR. REV. STAT. § 441.078 (2021).

116. DEL. CODE ANN. tit. 16, § 2743 (2021).

117. KAN. STAT. ANN. § 65-3276 (2021).

118. OHIO REV. CODE ANN. § 2108.36 (West 2021).

119. 20 PA. CONS. STAT. ANN. § 8613(i) (2021).

120. WASH. REV. CODE § 68.70.020 (2021).

121. LA. STAT. ANN. §§ 40:1170.1-1170.4 (2021).

122. IND. CODE § 16-32-5-3 (2021).

123. VA. CODE ANN. § 32.1-297.2 (2021).

124. IOWA CODE § 135.192 (2021).

125. MO. REV. STAT. § 194.320 (2021).

126. FLA. STAT. § 765.523 (2021).

127. ARK. CODE ANN. § 20-14-902-903 (2021).

128. S.B. 378, 58th Leg., 1st Reg. Sess. (Okla. 2021).

129. WYO. STAT. ANN. § 35-5-302 (2021).

130. S.B. 305, 81st Sess. (Nev. 2021).

131. H.F. 2128, 92nd Leg. (Minn. 2021).

132. TENN. CODE ANN. § 68-31-102 (2021).

133. TEX. HEALTH & SAFETY CODE ANN. § 161.473 (2021).

(2021);<sup>134</sup> Colorado (2021);<sup>135</sup> Georgia (2021);<sup>136</sup> Illinois (2021);<sup>137</sup> North Carolina (2021);<sup>138</sup> Rhode Island (2021).<sup>139</sup> Some states passed these laws in response to specific cases, such as California<sup>140</sup> which passed its Uniform Anatomical Gift Act in response to the discrimination faced by Sandra Jensen.<sup>141</sup>

Every state's legislation differs in the level of detail included and protection offered. Some states' legislation includes a priority review provision requiring courts to give these cases priority in scheduling, in an effort to resolve disputes quickly.<sup>142</sup> Other states do not use the term priority, but require the court to "schedule a hearing as soon as possible,"<sup>143</sup> while other states do not address this issue at all.<sup>144</sup> Additionally, a large number of

134. S.B. 155, 67th Leg., Reg. Sess. (Mont. 2021).

135. COLO. REV. STAT. § 25-56-104 (2021).

136. H.B. 128, 156th Gen. Assemb., Reg. Sess. (Ga. 2021).

137. S.B. 0500, 102d Gen. Assemb., Reg. Sess. (Ill. 2021).

138. H.B. 642, Gen. Assemb., 2021 Sess. (N.C. 2021).

139. H.B. 6079, Gen. Assemb., 2021 Sess. (R.I. 2021).

140. Additional examples: New Jersey passed its legislation in response to Amelia Rivera's case and Pennsylvania passed "Paul's Law"—in response to the case of Paul Corby. NAT'L COUNCIL ON DISABILITY, *supra* note 3, at 57–59. Louisiana passed "Evie's Law," named after Evangeline Love Pearl. Courtenay Tucker, *3-Year-Old with Down Syndrome Inspires Game-Changing Organ Transplant Law*, KMBC NEWS (Feb. 28, 2020, 1:44 PM), <https://www.kmbc.com/article/3-year-old-with-down-syndrome-inspires-game-changing-organ-transplant-law/31120336> [<https://perma.cc/GWC9-9NSP>]. Virginia passed its statute named for Sawyer Shelor. Rachel Lucas, *Christiansburg Mother's Love Prompts Lifesaving Legislation to Protect the Disabled from Discrimination*, WSLs (Feb. 12, 2020, 5:43 PM), <https://www.wsls.com/news/local/2020/02/12/christiansburg-mothers-love-prompts-lifesaving-legislation-to-protect-the-disabled-from-discrimination> [<https://perma.cc/P5KL-PLJD>].

141. Ne'eman et al., *supra* note 6, at 5.

142. California (CAL. HEALTH & SAFETY CODE § 7151.35(d) (West 2021)); New Jersey (N.J. REV. STAT. §§ 26:6-86.1–6-86.2 (2021)); Oregon (OR. REV. STAT. ANN. § 441.078(7) (2021)); Delaware (DEL. CODE ANN. tit. 16, § 2744(b) (2021)); Washington (WASH. REV. CODE § 68.70.030 (2021)); Louisiana (LA. STAT. ANN. § 40:1170.4.B (2021)); Iowa (IOWA CODE § 135.192.4 (2021)); Missouri (MO. REV. STAT. § 194.320.3 (2021)); Oklahoma (S.B. 378, 58th Leg., 1st Reg. Sess. (Okla. 2021)); Wyoming (WYO. STAT. ANN. § 35-5-303(b) (2021)); Nevada (S.B. 305, 81st Sess. (Nev. 2021)); Tennessee (TENN. CODE ANN. § 68-31-103(b) (2021)); Montana (S.B. 155, 67th Leg., Reg. Sess. (Mont. 2021)); Colorado (COLO. REV. STAT. § 25-56-105(2) (2021)); Georgia (H.B. 128, 156th Gen. Assemb., Reg. Sess. (Ga. 2021)); Illinois (S.B. 0500, 102d Gen. Assemb., Reg. Sess. (Ill. 2021)); North Carolina (H.B. 642, Gen. Assemb., 2021 Reg. Sess. (N.C. 2021)); Rhode Island (H.B. 6079, Gen. Assemb., Reg. Sess. (R.I. 2021)).

143. Maryland (MD. CODE ANN., HEALTH–GEN. § 20-1606(b) (West 2021)); Kansas (KAN. STAT. ANN. § 65-3276(g) (2021)); Arkansas (ARK. CODE ANN. § 20-14-904(b) (2021)); *see also* Ohio (OHIO REV. CODE ANN. § 2108.37 (West 2021) (requiring the court to "schedule a hearing as soon as practicable")); Indiana (IND. CODE § 16-32-5-7(b) (2021) (same)); Tennessee (TENN. CODE ANN. § 68-31-103(b) (2021) (same)).

144. Massachusetts (MASS. GEN. LAWS ch. 111, § 236 (2021)); Pennsylvania (20 PA. CONS. STAT. ANN. § 8613(i) (2021)); Florida (FLA. STAT. § 765.523 (2021)); Minnesota (H.F. 2128, 92nd Leg. (Minn. 2021)); Texas (TEX. HEALTH & SAFETY CODE ANN. § 161.473 (2021)).

states explicitly list what types of relief can be sought.<sup>145</sup> Almost all current state legislation specifies that a person with a disability seeking an organ transplant is not required to show that they can comply with post-transplant requirements independently.<sup>146</sup> All of the current laws stipulate that medical professionals may take into account a person's disability if the person's disability is deemed to be "medically significant" to receiving the organ transplant, although none of the statutes adequately explain what "medically significant" actually means. The text of each state's legislation will be further analyzed in Part III.D and Part IV of this Note.

### C. STATE LEGISLATION: MILESTONE OR GESTURE?

State legislation prohibiting discrimination against people with disabilities has yet to authentically protect people with I/DD. To effectively protect individuals, state legislation must evolve. Although state legislation has been ineffective, the mere existence of this type of legislation—in a steadily increasing number of states—demonstrates significant growth towards equal treatment for people with I/DD in the organ transplant process. However, while these statutes as a whole indicate progress, in actuality, they have many shortcomings.

State laws are currently insufficient in providing protection for people with I/DD in the organ transplant process. Many transplant centers, in states that have passed this type of legislation, list guidelines and restrictions on their websites that blatantly contradict the law of their state.<sup>147</sup> One possible reason for continued discrimination is that medical professionals may not know that these state laws exist or they may not understand which disabilities are covered by the applicable laws.<sup>148</sup> Alternatively, the state laws simply may not be adequately enforced. Additionally, although part of the motivation for state

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145. Oregon (OR. REV. STAT. § 441.078 (2021)); Louisiana (LA. STAT. ANN. § 17:2353(M) (2021)); Virginia (VA. CODE ANN. § 32.1-297.2 (2021)); Wyoming (WYO. STAT. ANN. § 35-5-303(b) (2021)); Oklahoma (S.B. 378, 58th Leg., 1st Reg. Sess. (Okla. 2021)); Montana (S.B. 155, 67th Leg., Reg. Sess. (Mont. 2021)); Colorado (COLO. REV. STAT. § 25-56-105(2) (2021)); Georgia (H.B. 128, 156th Gen. Assemb., Reg. Sess. (Ga. 2021)); Massachusetts (MASS. GEN. LAWS ch. 111, § 236(i)(3) (2021)); North Carolina (H.B. 642, Gen. Assemb., 2021 Sess. (N.C. 2021)); Rhode Island (H.B. 6079, Gen. Assemb., 2021 Sess. (R.I. 2021)).

146. Ohio, Indiana, and Tennessee are the only statutes that do not. See OHIO REV. CODE ANN. § 2108.36 (West 2021); IND. CODE § 16-32-5-5 (2021) (addressing the issue of compliance without specifying "independent compliance"); TENN. CODE ANN. § 68-31-102 (2021) (same).

147. See NAT'L COUNCIL ON DISABILITY, *supra* note 3, at 54-55. Several examples of this conduct include: St. Joseph Hospital in California; University of Pennsylvania's lung and kidney programs; and Pittsburgh Medical Center. See *id.* at 54.

148. *Id.* at 59 (stating that California and New Jersey specifically enacted legislation for developmental disabilities so "some physicians and organ transplant centers may not be aware that legal protections also extend to other types of disabilities").

legislation is to give patients and their families an easier path for bringing a cause of action,<sup>149</sup> there are no published cases, to date, applying these laws.<sup>150</sup>

D. CURRENT STATE LAWS DO NOT ADEQUATELY HOLD  
PHYSICIANS ACCOUNTABLE

The main reason these current state laws do not provide adequate protection is that the statutes' text and provisions are not comprehensive enough. State legislation currently attempts to "balance . . . the protections of rights of the disabled [with] . . . physician autonomy in clinical judgment."<sup>151</sup> However, state legislation does not draw clear lines between a physician's clinical discretion and discriminatory actions.<sup>152</sup>

State legislation does not provide adequate clarification to physicians as to what actions may or may not constitute discrimination against people with disabilities in the organ transplant process. State laws only warn a medical professional that they cannot make certain decisions "solely on the basis of a qualified individual's disability."<sup>153</sup> More specifically, most state statutes tell a physician that they may not, based only on a patient's disability, classify an individual as transplant ineligible, deny a patient an evaluation or any other medical services related to an organ transplant, refuse to refer a patient to a transplant center, or refuse to place a patient on an organ transplant waiting list.<sup>154</sup> Most state laws attempt to clarify this by asserting that physicians "may take an individual's disability into account when making treatment or coverage recommendations or decisions *solely to the extent* that the physical or mental disability has been found by a physician . . . to be medically significant."<sup>155</sup> This only adds more room for the physician's medical knowledge and discretion to stealthily mask discrimination. The discretion afforded to medical professionals also makes it more challenging for patients to recognize when they are being discriminated against.<sup>156</sup>

149. See *id.* at 57–60 (discussing how many states have included a provision requiring priority review by courts).

150. For possible reasons as to why there are no federal cases, see *supra* Section III.A.

151. Frank, *supra* note 62, at 134.

152. See *infra* notes 153–56 and accompanying text.

153. See, e.g., OR. REV. STAT. § 441.078(2) (2021) (emphasis added).

154. See, e.g., *id.*

155. See, e.g., MASS. GEN. LAWS ch. 111, § 236(c) (2021) (emphasis added).

156. An example of a patient struggling to recognize discrimination:

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

NAT'L COUNCIL ON DISABILITY, *supra* note 3, at 50 (footnotes omitted).

A number of factors influence a physician's discretion, not the least of which is the fact that organs are a scarce resource, and as such, they must be allocated in a strategic manner.<sup>157</sup> This factor often leads physicians to prioritize.<sup>158</sup> the goal "that organs . . . be . . . given to patients most likely to benefit or in whom the graft would survive the longest."<sup>159</sup> Therefore, a physician's concern "for comorbidities related to the cognitive disability" can conceal discriminatory actions by physicians, thus making it difficult to detect when discrimination actually occurs.<sup>160</sup> Beyond that, "[p]hysicians . . . may never recognize" that they are making decisions based on discriminatory reasons, "viewing their decisions within the context of best allotment of a scarce organ."<sup>161</sup> Accordingly, current state laws that only caution physicians to not consider a person's disability does not give the physician enough direction. Current state laws indirectly allow physicians to continue making discriminatory decisions, because they do not guide medical professionals as to where the line lies between a discriminatory action and a discretionary action.

#### IV. IMPORTANT PROVISIONS THAT STATE LAWS SHOULD INCLUDE TO BE EFFECTIVE

State laws prohibiting discrimination against people with disabilities in the organ transplant process differ from state to state. To remedy the glaring inconsistencies, loopholes, and shortfalls amongst the states as previously explored in Part III, all states should pass and/or amend their state codes to contain particular provisions. To that end, Part IV identifies which aspects of current state legislation are important and necessary for other states to adopt in future legislation or add to current legislation. State law is the appropriate legal framework through which to address the discrimination issues identified in this Note because federal litigation can often take years to resolve,<sup>162</sup> and organ transplant decisions are extremely time sensitive in nature.<sup>163</sup>

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157. See *id.* at 21.

158. See Allison Tong et al., *Rationing Scarce Organs for Transplantation: Healthcare Provider Perspectives on Wait-Listing and Organ Allocation*, 27 *CLINICAL TRANSPLANTATION* 60, 68 (2013) ("Many studies reported that most participants indicated that wait-listing and allocation of organs should be preferentially granted to patients who did not have suicidal ideations, HIV, AIDS, psychiatric illness, alcoholism, or substance abuse problems. They believed that patients who could manage their health and treatment successfully 'deserved priority.'").

159. See *id.* (discussing how physicians often have two competing goals in organ transplant decisions: to maximize clinical benefits and social outcome and to achieve equity).

160. Frank, *supra* note 62, at 124.

161. *Id.*

162. See NAT'L COUNCIL ON DISABILITY, *supra* note 3, at 13.

163. *Id.*

Many states follow the model state legislation laid out by the Autistic Self Advocacy Network (“ASAN”).<sup>164</sup> The ASAN model is an excellent springboard for future states considering passing a statute prohibiting discrimination against people with disabilities in the organ transplant process. The ASAN model appropriately prohibits “a covered entity”<sup>165</sup> from discriminating “solely on the basis of a qualified individual’s mental or physical disability.”<sup>166</sup> The ASAN model also includes a list of important definitions to clarify the meaning of the statute.<sup>167</sup> Future states looking to pass similar legislation should use the ASAN model as a foundation. In addition, this Note puts forth provisions that do not already exist in the model, which no or few states have adopted.<sup>168</sup> The Note specifically proposes provisions that: add physician accountability, expedite review, eliminate the notion of independent compliance, and add specific remedies and penalties.

#### A. PHYSICIAN ACCOUNTABILITY

State laws need to encourage physicians to recognize when they are making discriminatory decisions. It would be easy to simply suggest that state laws incorporate more specific language guiding physicians in exactly what it means to make a decision on the basis of a disability or to take into account the disability to the extent medically necessary. Yet, that may not be a possible or practical solution. Physicians have specialized knowledge that medical laymen, including most legislators, do not have. It would be inappropriate and unrealistic for legislatures to describe exactly how a physician must decide

164. See generally MODEL LEGISLATION: AN ACT CONCERNING NONDISCRIMINATION IN ACCESS TO ORGAN TRANSPLANTATION (AUTISTIC SELF ADVOC. NETWORK 2014), <https://autisticadvocacy.org/wp-content/uploads/2014/03/OrganTransplantationModelLegislation.pdf> [<https://perma.cc/5QPW-ZCCV>] (recommending sections pertaining to “[l]egislative intent,” “[d]efinitions,” prohibiting discrimination, and “[e]nforcement”).

165. The ASAN model defines “covered entity” as:

- a. Any licensed provider of health care services, including licensed health care practitioners, hospitals, nursing facilities, laboratories, intermediate care facilities, psychiatric residential treatment facilities, institutions for individuals with intellectual or developmental disabilities, and prison health centers; or b. Any entity responsible for matching anatomical gift donors to potential recipients.

*Id.* § 2(8).

166. *Id.* § 4(1).

167. These definitions include the terms “[d]isability,” “[a]uxiliary aids and services,” “[q]ualified individual,” “[r]easonable modification,” “[a]natomical gift,” “[o]rgan transplant,” “[s]upported decisionmaking,” and “[c]overed entity.” *Id.* § 2.

168. The provisions (that this Note discusses) that are in the ASAN model are the priority provision, the expedited review provision, and the provision specifying that a person does not need to independently comply with post-transplant medical requirements. *Id.* §§ 4(3), 5(2). States that already have existing legislation should amend their statutes to include any relevant provisions, outlined in Sections IV.A–E of this Note, that are not already included in their statutes. This Note does not review every provision in the ASAN model, or in actual state legislation, that should be included or addressed in amended state statutes.

whether to accept a patient as a transplant candidate.<sup>169</sup> Taking into account medical advancements and technologies, state laws should be written in a way that encourages *informed* medical decision-making and that holds individual physicians and/or transplant centers accountable for discrimination.

Physicians need to be conscious of why they are making a decision to deny organ transplants to people with I/DD. To this end, one proposal is to require physicians to sign a uniform disclosure form forcing them to acknowledge that they declined a patient for a transplant “[w]ithout consideration of this patient’s cognitive abilities and/or intellectual disability . . . and [that the patient] would not otherwise have been deemed eligible for transplant.”<sup>170</sup> This proposal successfully “avoids impeding or regulating physicians’ clinical judgment, yet helps to ensure that the basis of their clinical judgment is rooted in relevant legal and ethical factors.”<sup>171</sup> Nevertheless, that proposed solution still allows physicians to conceal discriminatory decisions by their own clinical judgment.<sup>172</sup> Forcing physicians to sign such a statement may help them become aware of their own discrimination based on subconscious bias. However, it does not allow for laymen—including courts, legislatures, patients, or patients’ families—to enforce such a statement or hold the physician accountable.

State laws should instead include a provision that requires physicians to document the precise *medical justification* for denying a person with disabilities as a candidate for organ transplantation. The provision should also require physicians to sign a statement acknowledging why they denied an organ transplant to a person with disabilities.<sup>173</sup>

This provision should provide the following:

If a covered entity deems an individual ineligible to receive an anatomical gift or organ transplant, the covered entity is responsible for documenting the reasons why the physician or surgeon found the individual’s physical or mental disability<sup>174</sup> to be medically significant to the provision of the anatomical gift. A covered entity must require a physician or surgeon who finds an individual with a disability ineligible to receive an anatomical gift to sign a form to be included in the patient’s medical file. The form must be signed and dated by the physician or surgeon that made the decision; it must be

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169. See Frank, *supra* note 62, at 128 (discussing how medical experts should retain autonomy in medical decisions as they hold more knowledge of the transplants and the medical intricacies than a legislature or a court).

170. *Id.* at 134.

171. *Id.*

172. See *supra* notes 157–61 and accompanying text.

173. See *supra* notes 170–71 and accompanying text.

174. Although this Note only discusses intellectual and developmental disabilities, state laws prohibiting discrimination against people with disabilities in the organ transplant process, cover all disabilities, including physical disabilities.

signed by the individual seeking an organ transplant or if not medically competent, an appropriate representative; it must list the specific reasons why the physician or surgeon found the individual to be ineligible for the anatomical gift; it must list why, if at all, the individual's physical or mental disability is medically significant to the provision of the anatomical gift; and it must include the following clause:<sup>175</sup>

A "disability" includes a physical or mental impairment that substantially limits one or more major life activities of such individual, a record of such an impairment, or being regarded as having such an impairment.<sup>176</sup>

Without consideration of this patient's disability, this patient was declined for transplant and would not otherwise have been deemed eligible for transplant. Since it is unlawful to discriminate against candidates solely on the basis of disabilities, this statement serves to confirm that the intellectual disability did not play a determinative role in the patient's candidacy for transplant, except where the patient's disability is medically significant, decreasing the probability of successful transplantation. This statement is signed under the penalty of state law. State and federal law prohibits the discrimination of people with disabilities in the organ transplant process.<sup>177</sup>

This provision would hold physicians accountable and would help fill the gap created by the vague language in state statutes which allows physicians to take a person's disability into account to the extent medically necessary.<sup>178</sup> Forcing physicians to lay out the exact medical reason would allow patients and courts to recognize when a physician was taking a person's disability into account beyond the extent that is medically necessary and thus when a physician was breaking the law. Furthermore, it would force a physician to stop and think about the exact medical justification for denying an individual an anatomical gift, which may help decrease some physicians' unconscious biases.

Furthermore, this addition to state legislation will inform medical professionals, transplant centers, patients, and patient's families that state laws

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175. The author's own language. Inspired by the organ transplant model legislation proposed by Autistic Self Advocacy Network. See generally MODEL LEGISLATION: AN ACT CONCERNING NONDISCRIMINATION IN ACCESS TO ORGAN TRANSPLANTATION (AUTISTIC SELF ADVOC. NETWORK 2014) (recommending sections pertaining to "[l]egislative intent," "[d]efinitions," prohibiting discrimination, and "[e]nforcement").

176. Language adapted from the ADA. 42 U.S.C. § 12102 (2021).

177. Language taken and adapted from Sarah Frank's proposed uniform nondisclosure statement. See Frank, *supra* note 62, at 134.

178. See *supra* note 155 and accompanying text.

exist prohibiting discrimination against people with disabilities in the organ transplant process. Many medical professionals do not know that it is illegal<sup>179</sup> to make decisions in the organ transplant process on the basis of an individual's disability.<sup>180</sup> Forcing a physician and patient, or patient's family, to sign a statement acknowledging that it is against state and federal law to discriminate on the basis of an individual's disability will act as a delivery device. It will inform physicians and patients that legislation exists specifically protecting the civil rights of an individual with a disability in the organ transplant process.<sup>181</sup> If a patient is informed that these laws exist, the patient and their family may make an informed decision to bring a cause of action against the physician or transplant center if they suspect that discrimination.

### B. PRIORITY AND EXPEDITED REVIEW

State legislation needs to include a priority and expedited review provision in order to be effective in protecting people with I/DD in the organ transplant process. Most state statutes, but not all, include a provision that requires courts to put cases that are brought under the state statute at the forefront of their dockets and expedite the review of the case.<sup>182</sup> The provision often states that “[t]he court shall accord *priority* on its calendar and *expeditiously* proceed with an action brought to seek any remedy authorized by law for purposes of enforcing compliance with the provisions of this Act.”<sup>183</sup>

A state statute must include a priority and expedited review provision to be truly effective in shielding people with I/DD from discrimination in the organ transplant process. Individuals seeking an organ transplant are racing the clock and often may die without one. Therefore, a patient that has been discriminated against because of their I/DD does not have the time to bring a cause of action against a transplant center for discrimination. If a patient has been denied an organ transplant and the patient, or the patient's family, suspects that they have been discriminated against based on I/DD, then the patient needs a timely solution. Priority and expedited review give patients a chance to receive the organ transplant and, in turn, a chance to possibly live a longer life (if the court reverses the transplant center's decision).<sup>184</sup>

### C. ACCEPTING LACK OF INDEPENDENT COMPLIANCE

Furthermore, state statutes must include a clause recognizing that a person does not have to be capable of *independently* complying with post-transplant requirements. All current state statutes contain a provision similar

179. Federal law applies even in states that have yet to adopt state legislation.

180. NAT'L COUNCIL ON DISABILITY, *supra* note 4, at 51.

181. See *supra* note 153–56 and accompanying text.

182. Some states only include a priority review provision but fail to mention expedited review.

183. MODEL LEGISLATION: AN ACT CONCERNING NONDISCRIMINATION IN ACCESS TO ORGAN TRANSPLANTATION § 5(2) (AUTISTIC SELF ADVOC. NETWORK 2014) (emphasis added).

184. See NAT'L COUNCIL ON DISABILITY, *supra* note 3, at 60.

to the following: “[i]f an individual has the necessary support system to assist the individual in complying with post-transplant medical requirements, an individual’s inability to independently comply with those requirements shall not be deemed to be medically significant for the purposes of [this] paragraph . . . .”<sup>185</sup>

This provision is imperative because many medical professionals allow an individual’s inability to independently follow postoperative care to influence their decision in denying an organ transplant.<sup>186</sup> However, “[i]f a person with a disability receives adequate support, the person’s disability should . . . have very limited impact on the ability to adhere to a post-transplant care regimen.”<sup>187</sup> Therefore, state statutes must directly inform medical professionals that independent non-compliance should not, and cannot, be considered when evaluating a person with a disability for an organ transplant.

#### D. SPECIFIC RELIEF

State statutes must properly advise courts as to what relief is available for the individual. Not enough states currently detail what relief is available to plaintiffs. Statutes should not only dictate that an action can be brought seeking equitable or injunctive relief, but also directly specify what that relief may look like. The Massachusetts’ statute is one of the states to do this most successfully.<sup>188</sup> It instructs courts that they can:

- (i) grant such equitable relief as it considers appropriate, to the extent required by this section;
- (ii) grant injunctive, temporary, preliminary or permanent relief;
- (iii) require an auxiliary aid or service or the modification of a policy, practice or procedure or require an alternative method;
- (iv) require that facilities shall be made readily accessible to and usable by individuals with disabilities;
- (v) award such other relief as the court considers appropriate, including monetary damages to aggrieved persons.<sup>189</sup>

Other states—in future or current legislation—should adopt a similar provision to guide courts as to what relief is available. This in turn would speed

185. MODEL LEGISLATION: AN ACT CONCERNING NONDISCRIMINATION IN ACCESS TO ORGAN TRANSPLANTATION § 4(3) (AUTISTIC SELF ADVOC. NETWORK 2014).

186. NAT’L COUNCIL ON DISABILITY, *supra* note 3, at 12.

187. *Id.* at 13.

188. Other states that have adopted a similar provision include: Oregon (OR. REV. STAT. § 441.078(8) (2021)); Louisiana (LA. STAT. ANN. § 40:1170.4.B (2021)); Virginia (VA. CODE ANN. § 32.1-297.2.F (2021)); Wyoming (WYO. STAT. ANN. § 35-5-303(b) (2021)); Oklahoma (S.B. 378, 58th Leg., 1st Reg. Sess. (Okla. 2021)); Montana (S.B. 155, 67th Leg., Reg. Sess. (Mont. 2021)); Colorado (COLO. REV. STAT. § 25-56-105(2) (2021)); Georgia (H.B. 128, 156th Gen. Assemb., Reg. Sess. (Ga. 2021)); North Carolina (H.B. 642, Gen. Assemb., 2021 Sess. (N.C. 2021)); Rhode Island (H.B. 6079, Gen. Assemb., 2021 Sess. (R.I. 2021)).

189. MASS. GEN. LAWS ch. 111, § 236(i)(3) (2021).

up the litigation process and also ensure that claimants receive the appropriate relief.

### E. SPECIFIC PENALTIES

State laws must also guide courts as to what penalties they can, and should, place upon the physician or transplant center for discriminating on the basis of disability. Currently, no states properly address penalties a court may impose on a party that violates the law.<sup>190</sup> If “[n]o specific penalties or remedies are set forth in the statute to encourage compliance,’ . . . the law [is] less powerful in preventing discrimination.”<sup>191</sup> State statutes should list the appropriate penalties—including, but not limited to monetary penalties—that a court may place upon the violating covered entity. Ultimately, though, the court should have discretion to decide the appropriate penalty on a case-by-case basis. Transplant centers are more likely to comply with the law, including the provision set out in Section IV.A, if they risk some loss.<sup>192</sup> Additionally, transplant centers are more likely to monitor the actions of the physicians and to inform physicians of such laws if they are penalized for any discriminatory conduct that they may be held accountable.

### V. CONCLUSION

People with I/DD are often discriminated against throughout the lifesaving organ transplant process. Federal laws exist that prohibit this type of discrimination, but those laws are often inadequate in practice. This Note focused on state law, where the law is more rapidly evolving.<sup>193</sup> As of the summer of 2021, 29 states and counting have adopted legislation specifically prohibiting discrimination on the basis an individual’s disability in the organ transplant process. Yet, the existing state laws do not provide adequate protection for people with I/DD. State legislation must contain specific language that holds medical professionals and transplant centers accountable as well as language that guides courts on to how to handle these cases. This Note outlined provisions that states currently with such statutes should add and states without such statutes should include in future legislation to be effective in protecting individuals with I/DD from pervasive discrimination.

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190. Currently only Massachusetts addresses penalties at all, and only to limit the amount a court may assess against a covered entity that has violated the law. *Id.* (“In addition, the court may assess a civil penalty against a covered entity of not more than \$50,000 for a first violation and not more than \$100,000 for a second or subsequent violation.”).

191. NAT’L COUNCIL ON DISABILITY, *supra* note 3, at 60 (first alteration in original) (footnote omitted) (quoting Frank, *supra* note 62, at 113).

192. *See id.*

193. Although this Note did not offer guidance as to what changes should be made at the federal level, other changes should and can be made in conjunction with states passing effective legislation, including adding the provisions suggested by this Note to the Charlotte Act or any federal bill introduced thereafter.