

Access to Health Care and the Intellectually and Developmentally Disabled: Anti-Discrimination Law, Health Law, and Quality of Life

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I. INTRODUCTION

Over the past few years, the national headlines have been filled with stories that are shaping society’s understanding and view of individuals with intellectual and developmental disabilities. In 2016, Asher Nash, a sixteen-month-old with Down syndrome, was featured as a model in the holiday campaign for clothing company OshKosh B’Gosh after a modeling agency turned him down.¹ In 2017, twenty-two-year-old Mikayla Holmgren grabbed national attention when she was the first contestant with Down syndrome to compete in the Miss

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¹ Jennifer Earl, *Toddler with Down Syndrome Stars in OshKosh B’Gosh Holiday Ad*, CBS NEWS (Dec. 6, 2016), <https://www.cbsnews.com/news/toddler-with-down-syndrome-stars-in-oshkosh-bgosh-holiday-ad>.

USA pageant.² In 2018, the Gerber food company selected Lucas Warren, a baby with Down syndrome, as its Gerber baby.³ Additionally, in 2018, Kayla McKeon, was the nation's first national lobbyist with Down syndrome.⁴ These real life examples have been praised in the media as showing the value of those with intellectual and developmental disabilities as well as their inclusion in society.

State legislatures have acted in response to the needs of this growing population on the legislative stage by drawing national attention to issues through legislation on the state level that will ultimately shape the national view of disability regarding issues of health care access where federal protections have proven inadequate or non-enforceable. A specific example of this is seen by several states which have passed anti-discrimination legislation to prevent the intellectually or developmentally disabled from being denied eligibility for placement on an organ transplant list in response to a lack of federal legal guidance on the issue.⁵ These legislative efforts suggest a trend in which states are abandoning quality of life assessment as a determinant measurement for the legal rights of an individual with an intellectual or developmental disability. The World Health Organization (WHO) defines "quality of life" as

an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs,

² Janice Williams, *Who Is Mikayla Holmgren? First Woman to Compete for Miss USA State Pageant Crown with Down Syndrome*, NEWSWEEK (Nov. 27, 2017, 2:19 PM), <http://www.newsweek.com/mikayla-holmgren-miss-usa-pageant-723561>.

³ Ashley May, *First Baby with Down Syndrome Wins Gerber Baby of the Year*, USA TODAY (Feb. 7, 2018, 11:40 AM), <https://www.usatoday.com/story/news/nation-now/2018/02/07/first-baby-down-syndrome-wins-gerber-baby-year/315089002>.

⁴ Courtney Perkes, *New York Woman Is Nation's First Lobbyist With Down Syndrome*, DISABILITY SCOOP (June 26, 2018), <https://www.disabilityscoop.com/2018/06/26/new-first-lobbyist-down-syndrome/25237>.

⁵ 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?utm_term=.47c96c4c58a2.

social relationships and their relationship to salient features of their environment.⁶

It is clear that this assessment is actually based on an individual's own perceptions of his or her life. In the context of medical decision-making of an individual's eligibility for an organ transplant, the use of a quality of life assessment allows medical professionals to make judgment calls on the anticipated value or worth of an individual's life post-transplant, which often forms part of the basis for a medical center's determination of an individual's ultimate eligibility to be placed on an organ transplant waitlist.⁷ However, quality of life assessments are "inherently subjective" because they cannot be made based on any particular measurable standard and are contrary to the stated federal goals for transplant decision-making to be based on objective and measurable medical standards.⁸

In February 2014, the Harvard Ethics Leadership Group, through the Community Ethics Committee, released a report that detailed the organ transplant decision-making process and specifically examined the process with regard to intellectually and developmentally disabled children.⁹ The Community Ethics Committee ultimately determined that quality of life should not factor into the determination for eligibility of an individual with an intellectual or developmental disability on an organ transplant list by medical professionals.¹⁰ This movement away from quality of life also appears to be accompanying an observed shift from a medical to a social model of disability or some variation from what has typically permeated issues involving health care access issues. Generally, the medical model of disability views disability as a medical condition that needs to be fixed or altered for the individual with a disability to be included; alternatively, the social model views disability in the context of the barriers that society has created that need to be remedied to allow the person with a disability full access to participation in society.¹¹ Can, or should, quality of life assessment be completely eliminated? Should there be a movement away from

⁶ *WHOQOL: Measuring Quality of Life*, WORLD HEALTH ORG., <https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en> (last visited Aug. 26, 2019).

⁷ ORGAN TRANSPLANT RECIPIENT LISTING CRITERIA, COMMUNITY ETHICS COMMITTEE 13 (2014), <https://bioethics.hms.harvard.edu/sites/g/files/mcu336/f/CEC-REPORT-Organ-Transplant-Listing-Criteria-February-2014.pdf> [hereinafter COMMUNITY ETHICS COMMITTEE].

⁸ *Id.* at 6.

⁹ *Id.* at 1.

¹⁰ *Id.* at 13.

¹¹ *Definitions of the Models of Disability*, DISABLED WORLD, <https://www.disabled-world.com/definitions/disability-models.php> (last revised Dec. 2, 2017).

the medical model of disability in favor of the social model or a hybrid model of disability regarding health care access for the disabled?

This Article will examine this legislative trend in regulating organ transplants of the intellectually and developmentally disabled. First, this Article will examine the relevant statistics regarding organ donation transplants, some of the well-known cases regarding individuals with intellectual and developmental disabilities, and their families who have fought for organ transplants after denials based on disability, which have sometimes led to legislative responses from various states, as well as other instances of movement for legal changes on this issue. Next, this Article will explore the issue of organ transplant regarding the intellectually disabled in terms of the consideration of the quality of life assessment that frequently occurs in these determinations. Finally, this Article will examine how the different models of disability theory can have a significant impact on how policy is developed in health care issues for the disabled.

II. ORGAN TRANSPLANTS: STATISTICS, SCIENCE, AND NOTABLE CASES INVOLVING INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

According to the U.S. Government Information on Organ Donation and Transplantation through the U.S. Department of Health and Human Services (HHS), 113,000 individuals were on the national transplant waiting list as of January 2019.¹² “Each year, the number of people on the waiting list continues to be much larger than both the number of donors and transplants, which grow slowly.”¹³ Approximately “every [ten] minutes, another person is added to the waiting list.”¹⁴ It is estimated that “[twenty] people die each day waiting for a transplant.”¹⁵ While these numbers are staggering, research suggests that people with intellectual and developmental disabilities have experienced a greater hurdle to organ transplant due to a history of discrimination on the basis of disabil-

¹² Organ Donation Statistics, HEALTH RESOURCES & SERVS. ADMIN., <https://www.organdonor.gov/statistics-stories/statistics.html> (last updated Jan. 2019).

¹³ *Id.*

¹⁴ *Id.*

¹⁵ *Id.*

ity to gain access to these life-saving procedures.¹⁶ This can be traced back to at least the 1990s.¹⁷ The earliest notable study occurred in 1992:

A 1992 survey of 411 transplant centers by Levenson and Olbrisch found that individuals with IQs between 50 and 70 would be considered absolutely contraindicated from receiving a heart transplant in 25% of transplant centers, with 59% stating a relative contraindication. When the same question was asked for patients with IQs under 50, almost 3 in every 4 transplant centers indicated an absolute contraindication. More recent data supports these concerns as well, while suggesting that some progress has been made since the [sic] Levenson and Olbrisch's 1992 survey.¹⁸

More recent studies have also demonstrated the continuance of this trend of individuals being determined ineligible for organ transplants based on the presence of a disability.¹⁹ A 2008 study at Stanford University further explored this phenomenon, finding the most blatant examples of such treatment in the context of decisions regarding eligibility for heart transplantation:

A 2008 survey of 88 transplant centers conducted by researchers at Stanford University found that 85% of pediatric transplant centers consider neurodevelopmental status as a factor in their determinations of transplant eligibility at least some of the time, with heart transplant centers being more restrictive in their decisions than kidney or liver programs. For example, 46% of heart programs indicated that even mild or moderate cognitive impairment would be a relative contraindication to eligibility, whereas no liver or kidney programs considered such levels of impairment to be a relative contraindication. 71% of heart programs surveyed always or usually utilized neurodevelopmental status in determinations of eligibility for transplantation, while only 30% and 33% of kidney

¹⁶ ARI NE'EMAN ET AL., ORGAN TRANSPLANTATION AND PEOPLE WITH I/DD: A REVIEW OF RESEARCH, POLICY AND NEXT STEPS 2–3 (2013), http://autisticadvocacy.org/wp-content/uploads/2013/03/ASAN-Organ-Transplantation-Policy-Brief_3.18.13.pdf.

¹⁷ *See id.* at 2.

¹⁸ *Id.*

¹⁹ *See id.* at 3.

and liver programs utilized such factors. Evidence suggests that insofar as progress in addressing discriminatory practice has been made, it has been weakest in the context of heart transplantation. The International Society for Heart and Lung Transplantation's heart transplantation criteria specifically states, "Mental retardation or dementia may be regarded as a relative contraindication to transplantation."²⁰

It is important to note that "62% of all programs indicated that informal processes guided their use of neurodevelopmental status as a decision-making factor and no programs described their process as 'formal, explicit, and uniform.'"²¹ Such variance in decision-making processes makes it extremely difficult to prove discrimination.²² Perhaps even more startling is how early in the organ transplant process individuals with intellectual and developmental disabilities have been eliminated from eligibility.²³ Oftentimes,

[m]any potential transplant recipients never get as far as evaluation by a transplant center. The 2004 National Work Group on Disability and Transplantation survey reports that only 52% of people with I/DD requesting referral to a specialist for evaluation receive such a referral, and approximately a third of those for whom referral is provided are never evaluated.²⁴

While it is clear from these various studies that there has been different treatment of individuals with intellectual and developmental disabilities, the next question arises as to whether or not such a denial for organ transplant eligibility is based on scientific support to justify such decisions. Numerous studies reject the scientific conclusions that suggest individuals with intellectual and developmental disabilities will somehow be less successful in the organ transplant process.²⁵ The earliest of these studies on pediatric transplantation occurred in 2006, which showed that "little scientific data exists that might support the idea that intellectual or developmental disability would constitute a

²⁰ *Id.* (quoting Mandeep R. Mehra et al., *Listing Criteria for Heart Transplantation*, 25 J. HEART & LUNG TRANSPLANTATION 1024, 1034 (2006)).

²¹ *Id.*

²² See NE'EMAN ET AL., *supra* note 16.

²³ *Id.*

²⁴ *Id.* at 3.

²⁵ *Id.*

heightened risk of poorer outcomes in the aftermath of a transplantation procedure, provided necessary supports in postoperative regimen compliance were provided.”²⁶

As many as fifty studies involving kidney transplants for individuals with intellectual or developmental disabilities have specifically shown that success rates post-transplant have been comparable to those of individuals without disabilities.²⁷ Another 2006 Japanese study demonstrated the quality of life of individuals with intellectual or developmental disabilities increased after undergoing successful renal transplantations.²⁸ Finally, it has also been noted in the 2010 American Journal of Transplantation that mental retardation should not serve as a reason to exclude individuals from access to organ transplants.²⁹

The first well-known case involving organ transplantation of an individual with an intellectual or developmental disability occurred in 1995, with thirty-four year old Sandra Jensen.³⁰ Born with Down syndrome, Sandra’s parents were told she would never amount to anything.³¹ Yet in 1996, the L.A. Times released an article on Sandra, stating “[t]he struggle to bring those with mental disabilities into full, participatory citizenship is a fight that many believe to be the last great liberation movement in America. Sandra Jensen is that movement’s poster girl, its sweetheart, its point woman.”³²

Sandra had a hole in her heart that constantly leaked.³³ Despite attempts to treat her condition using medications, it came to a point where medications

²⁶ *Id.*

²⁷ *Id.*

²⁸ NE’EMAN ET AL., *supra* note 16, at 3.

²⁹ *Id.* (“To quote a 2010 review in the American Journal of Transplantation, ‘[c]urrently, there is no scientific evidence or compelling data suggesting that patients with MR should not have access to organ transplantation.’”).

³⁰ *Id.* at 1.

³¹ Celeste Fremon, “...*We Do Not Feel That Patients with Down Syndrome Are Appropriate Candidates for Heart-Lung Transplantation.*”: *These Words Were a Death Sentence for Sandra Jensen. And That, She Decided, Just Wasn’t Going to Happen.*, L.A. TIMES (Apr. 14, 1996), http://articles.latimes.com/1996-04-14/magazine/tm-58423_1_sandra-jensen.

³² *Id.*

³³ *Id.*

were no longer alleviating the issue.³⁴ Because of this, Sandra's cardiologist, Dr. Philip Bach, referred Sandra for cardiac evaluation, which determined that blood was leaking into Sandra's lungs and causing scarring.³⁵ Sandra would ultimately die without the necessary heart and lung transplants.³⁶ Both Dr. Bach and UCLA cardiologists recommended that Sandra receive a heart-lung transplant.³⁷ Initially, the process for transplants appeared to be running smoothly for Sandra.³⁸ Her insurance company, Medi-Cal, authorized payment for the surgery.³⁹ The only contingency was that the surgery had to be performed by one of two California-based transplant centers, University of California San Diego (UC San Diego) or Stanford University, due to their one-year survival rate.⁴⁰ In February 1995, Dr. Bach approached Stanford University on behalf of Sandra with the necessary paperwork.⁴¹ Stanford University was not only renowned for having performed the first heart transplant in the United States, but also the first heart-lung transplant.⁴² But what occurred next was not expected or supposed to be part of the plan. Stanford University responded to Sandra's request for a heart-lung transplant with a letter stating, "[u]nfortunately, at this time, we do not feel that patients with Down syndrome are appropriate candidates for heart-lung transplantations."⁴³ The response came just three weeks after Dr. Bach submitted Sandra's paperwork.⁴⁴ The L.A. Times described Stanford's decision at this time as "a death sentence."⁴⁵ Dr. Bach immediately contacted UC San Diego to take Sandra's case.⁴⁶ While UC San Diego did take the time to evalu-

³⁴ *Id.*

³⁵ *Id.*

³⁶ *Id.*

³⁷ Fremon, *supra* note 31.

³⁸ *Id.*

³⁹ *Id.*

⁴⁰ *Id.*

⁴¹ *Id.*

⁴² *Id.*

⁴³ Fremon, *supra* note 31.

⁴⁴ *Id.*

⁴⁵ *Id.*

⁴⁶ *Id.*

ate Sandra in person in June 1995 and was described as more accommodating than Stanford University for doing this, she received a similar, yet slightly distinct, rejection to the one from Stanford University.⁴⁷ The UC San Diego rejection stated:

I regret to inform you . . . that it is the recommendation of the transplant committee that Ms. Jensen not be a candidate for heart-lung transplantation at our program . . . Ms. Jensen is limited in her ability to have recall and memory . . . We are left with great concerns of her ability to not only adhere to the medical regimen require[d] of her, but to understand the complexities of the transplant procedure and the complication she will face after the transplantation . . .⁴⁸

Dr. Bach responded to both institutions, adamant on Sandra's behalf of her need for the heart-lung transplant.⁴⁹ His pleas were met with silence by both institutions.⁵⁰ Dr. Bach began his own research and discovered that there had not been a single individual with Down syndrome who had received a heart-lung transplant despite the procedure's fifteen year existence.⁵¹ Sandra, who was already an active disability advocate, began a public campaign that drew national attention to both medical institutions, which resulted in them being bombarded with letters on Sandra's behalf.⁵² Sandra's story was far from over. She hired an attorney who determined that both medical institutions violated the Rehabilitation Act of 1973 and informed both institutions of her intent to take legal action.⁵³ Based on this pressure, both institutions agreed to evaluate her again, and both institutions again expressed their reluctance to perform the surgery.⁵⁴ Stanford indicated that Sandra did not want the transplant, to which she responded by writing her own letter to Stanford that was made public by her supporters.⁵⁵

⁴⁷ *Id.*

⁴⁸ *Id.* (quoting the UC San Diego rejection letter).

⁴⁹ Fremon, *supra* note 31.

⁵⁰ *Id.*

⁵¹ *Id.*

⁵² *Id.*

⁵³ *Id.*

⁵⁴ *Id.*

⁵⁵ Fremon, *supra* note 31.

Stanford agreed to do another evaluation of Sandra and, despite the “risk,” ultimately agreed to put Sandra on the organ donation transplant list in January 1996.⁵⁶ As Sandra’s health was declining, her victory in getting on a waitlist was no guarantee she would survive long enough to receive the transplant, as the minimum wait at that time for most people was approximately one year.⁵⁷ Miraculously, Sandra’s mother received the phone call four days later that there was a heart and set of lungs available for her daughter.⁵⁸ After Sandra’s transplant operation was complete, she spent some time in the ICU for health issues until she was ultimately moved to a private room by mid-February.⁵⁹ A little over a year after her transplant, Sandra passed away in May 1997.⁶⁰

While Sandra’s life post-transplant was short, her legacy lives on through a law passed in California that advocates for fair treatment within the organ transplant lists for disabled individuals.⁶¹ In 1995, California became the first state to pass this type of legislation that specifically prohibits the discrimination of individuals with disabilities to be denied eligibility on organ transplant lists solely on the basis of disability.⁶² The California law states 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, except to the extent that the physical or mental disability has been found by a physician and surgeon, following a case-by-

⁵⁶ *Id.*

⁵⁷ *Id.*

⁵⁸ *Id.*

⁵⁹ *Id.*

⁶⁰ Reuters, *Transplant Patient with Down Syndrome Dies*, L.A. TIMES (May 25, 1997), http://articles.latimes.com/1997-05-25/news/mn-62466_1_lung-transplant.

⁶¹ *Id.*

⁶² Sara Frank, *Eligibility Discrimination of the Intellectually Disabled in Pediatric Organ Transplantation*, 10 J. HEALTH & BIOMED. L. 101, 111 (2014); NE’EMAN ET AL., *supra* note 16, at 5; Laura Whelan, *Allocating Organs to Those with Down Syndrome: Compliance as a Scapegoat*, BIOETHICS PROJECT (Feb. 10, 2014), <http://blogs.kentplace.org/bioethicsproject/2014/02/10/allocating-organs-syndrome-compliance-scapegoat/>. See CAL. HEALTH & SAFETY CODE § 7151.35 (West 2008).

case evaluation of the potential recipient, to be medically significant to the provision of the anatomical gift.⁶³

After the national attention that was drawn to Sandra Jensen's case, many were hopeful that discrimination against individuals with intellectual or developmental disabilities in eligibility for placement on organ transplant lists was over. However, that has hardly been the case.

Following Sandra Jensen, the next notable case occurred in New Jersey in 2012 involving a 3-year-old girl named Amelia Rivera.⁶⁴ Amelia has a rare genetic condition known as Wolf-Hirschhorn syndrome.⁶⁵ The syndrome can potentially cause both physical and mental disabilities.⁶⁶ In this instance, the child's mother began blogging on the internet that she was told by a doctor at the Children's Hospital of Philadelphia that her daughter's quality of life and mental condition excluded her from eligibility for a necessary kidney transplant.⁶⁷ Similar to the case of Sandra Jensen, a public campaign developed for Amelia's need for a kidney transplant began via social media.⁶⁸ Support for Amelia and her family grew from the families of other special needs children who related to the experience of facing discrimination from medical professionals based on disability.⁶⁹ A Change.org petition gathered 50,000 signatures in support of Amelia and her family, as well as additional support on social media when Twitter users utilized #TeamAmelia.⁷⁰ Amelia's case did not seem to have quite so many hurdles as Sandra Jensen's, at least not publicly. The Children's Hospital of Philadelphia ultimately apologized for the decision which

⁶³ CAL. HEALTH & SAFETY CODE § 7151.35(a).

⁶⁴ Associated Press, *N.J. Girl, 3, Is Being Denied Kidney Transplant Because of Mental Abilities, Parents Claim*, NJ.COM (Jan. 18, 2012), http://www.nj.com/news/index.ssf/2012/01/nj_girl_3_is_being_denied_kidn.html.

⁶⁵ *Id.*

⁶⁶ *Id.*

⁶⁷ *Id.*

⁶⁸ *Id.*

⁶⁹ *Id.*

⁷⁰ Kim Painter & Nanci Hellmich, *Amelia Rivera Gets Kidney After Transplant Debate*, USA TODAY (July 30, 2013, 10:24 PM), <https://www.usatoday.com/story/news/nation/2013/07/30/amelia-rivera-kidney/2600551>.

was documented in a public statement on February 15, 2012.⁷¹ Amelia's mother, Chrissy Rivera, was the organ donor when Amelia's kidney transplant was successfully performed in July 2013.⁷² Also similar to the case of Sandra Jensen, Amelia's home state of New Jersey took legislative action in response to Amelia's experience. On July 18, 2013, Governor Chris Christie signed into law protections to prevent denials of organ transplant list eligibility based on disability.⁷³ Under New Jersey Statute:

An individual who is a candidate to receive an anatomical gift shall not be deemed ineligible to receive an anatomical gift solely because of the individual's physical or mental disability, except to the extent that the physical or mental disability has been found by a physician or surgeon, following an individualized evaluation of the potential recipient, to be medically significant to the provision of the anatomical gift. If an individual has the necessary support system to assist the individual in complying with post-transplant medical requirements, an individual's inability to independently comply with those requirements shall not be deemed to be medically significant. The provisions of this subsection shall apply to each part of the organ transplant process.⁷⁴

The New Jersey statute took one step further than the California statute by specifying the fact that the support network of the individual with intellectual or developmental disability should also be a consideration in the organ transplant decision-making process.

Another case that garnered national attention was that of Paul Corby from Pennsylvania, who at age 23, was denied an organ transplant by the University of Pennsylvania in 2011.⁷⁵ His mother had received a letter specifying that the denial of this necessary and life-saving heart transplant was due to "psychiatric

⁷¹ Joint Statement of the Rivera Family and The Children's Hospital of Philadelphia, WOLFHIRSCHHORN.ORG (Feb. 15, 2012), <http://wolfhirschhorn.org/2012/02/amelia/joint-statement-of-the-rivera-family-and-the-children%E2%80%99s-hospital-of-philadelphia>.

⁷² Painter & Hellmich, *supra* note 70.

⁷³ Susan K. Livio, *Christie Signs Bill Banning Hospitals and Doctors from Denying Disabled People Organ Transplants*, NJ.COM (July 18, 2013), http://www.nj.com/politics/index.ssf/2013/07/bill_banning_hospitals_and_doctors_from_denying_disabled_people_organ_transplants_now_law.html.

⁷⁴ N.J. STAT. ANN. § 26:6–86.2a (West 2013).

⁷⁵ Bernstein, *supra* note 5.

issues, autism, the complexity of the process . . . and the unknown and unpredictable effect of steroids on behavior.”⁷⁶ Similar to Amelia Rivera, a Change.org petition was started by Paul’s mother in an effort to convince the hospital to change its position.⁷⁷ An ethicist from the University of Pennsylvania responded that the government should not be in the business of essentially dictating medical decisions, but also suggested that transplant centers have largely free reign, as the system lacks checks and balances.⁷⁸ Since the writing of this article in March 2018, legislation introduced in Pennsylvania, initially known as “Paul’s Law,” to prevent discrimination on the basis of disability in organ transplants and finally was signed into law in 2018.⁷⁹ As of March 2019, Paul Corby is still waiting for a life-saving heart transplant as his mother unsuccessfully sought legal representation to sue for Paul’s denial for being placed on an organ transplant waitlist.⁸⁰

Another 2012 case involved Lief O’Neill, a nine-year-old with severe autism who was non-verbal.⁸¹ A virus left Lief in need of a life-saving heart transplant.⁸² Lief’s family attempted to have the organ transplant done in his home state of Oregon, but these attempts proved to be futile as the transplant teams

⁷⁶ *Id.*

⁷⁷ Rheana Murray, *23-year-old Pennsylvania Man with Autism Denied Heart Transplant by Hospital*, N.Y. DAILY NEWS (Aug. 16, 2012), <http://www.nydailynews.com/life-style/health/23-year-old-pennsylvania-man-autism-denied-heart-transplant-hospital-article-1.1137708>.

⁷⁸ Bernstein, *supra* note 5; *House Judiciary Committee Moves on Sabatina’s “Paul’s Law”*, PA SENATE DEMOCRATS (Mar. 14, 2018), <http://www.pasenate.com/house-judiciary-committee-moves-on-sabatinas-pauls-law>. See John P. Sabatina, Jr., Senator, *Senate Co-Sponsorship Memoranda: Paul’s Law—Prohibit Discrimination Against Disabled People in Need of Organ Transplants* (Dec. 2, 2016, 9:20 AM), <http://www.legis.state.pa.us/cfdocs/Legis/CSM/showMemoPublic.cfm?chamber=S&SPick=20170&cosponId=20988>.

⁷⁹ *Sabatina’s Anti-Discrimination Language Signed into Law by Governor Wolf*, ST. SENATOR JOHN SABATINA JR. (Nov. 14, 2018), <http://www.senatorsabatina.com/sabatinas-anti-discrimination-language-signed-into-law-by-governor-wolf>.

⁸⁰ Shira Stein, *Organ Transplant Disability Bias Gets Second Look Under Trump*, BLOOMBERG L. (Mar. 29, 2019), <https://news.bloomberglaw.com/health-law-and-business/organ-transplant-disability-bias-gets-second-look-under-trump>.

⁸¹ Sunshine Bodey, *Hospitals Denied My Child Life-Saving Surgery Because He was Autistic: Guest Opinion*, OREGON LIVE: OREGONIAN (Jan. 7, 2018), http://www.oregonlive.com/opinion/index.ssf/2018/01/hospitals_denied_my_child_life.html.

⁸² *Id.*

denied Lief on the basis of his disability.⁸³ Lief's mother wrote of the challenges to accessing an organ transplant that were based on his disability.

Needing a lifesaving transplant is truly awful for any child and family. For children with a disability, the challenges are even more immense. Lief has autism and is a non-speaking person who types to communicate. He struggles with sensory disturbance, profound motor planning difficulties and perseverance behaviors.

Because of our son's disability, the doctors at our local children's hospital told us that no facility would perform the transplant, and we should prepare for him to die. Then two other hospitals, one in Seattle and one in L.A., refused to consider him. That left Lief with only one last West Coast option. As Lief's condition swiftly deteriorated, a young physician at our local hospital pleaded his case to Lucile Packard Children's Hospital at Stanford University. The hospital was persuaded, and opened its doors to us.⁸⁴

It is interesting to note that it was a hospital at Stanford University that finally opened its doors to Sandra Jensen back in the '90s for an organ transplant, and it was now a Stanford University children's hospital opening its doors for Lief. It was medically risky to transport Lief from Oregon to California for the heart transplant.⁸⁵ Despite the odds, Lief had the transplant and came a long way in the five years since undergoing his heart transplant, to the point of using technology to speak to members of Oregon's legislature.⁸⁶ Oregon is now one of a handful of states that ultimately passed anti-discrimination legislation to prevent individuals with disabilities from being denied access to organ transplants solely on the basis of disability.⁸⁷

⁸³ *Id.*

⁸⁴ *Id.*

⁸⁵ *Id.*

⁸⁶ Chris Gray, *Legislature Paves Way for Organ Transplants for People with Disabilities*, LUND REP. (June 5, 2017), <https://www.thelundreport.org/content/legislature-paves-way-organ-transplants-people-disabilities>.

⁸⁷ *Nondiscrimination in Organ Transplantation Laws & Toolkit*, NAT'L DOWN SYNDROME SOC'Y, <https://www.ndss.org/advocate/ndss-legislative-agenda/healthcare-research/nondiscrimination-in-organ-transplantation-laws-toolkit> (last visited Sept. 7, 2019) [hereinafter NAT'L DOWN SYNDROME SOC'Y].

Despite the existence of federal laws to protect people with disabilities against discrimination, the desired protections for the disabled are still not a reality. These laws and policies are too difficult to enforce to address the issue of individuals with disabilities being denied access to organ transplant lists. Federal laws and procedures in place include the Americans with Disabilities Act of 1990 (ADA), Section 504 of the Rehabilitation Act of 1973, and processes within the U.S. Department of Health and Human Services.⁸⁸ Oversight of federal protections to health care under both the Rehabilitation Act of 1973 and the ADA is provided by the U.S. Department of Health and Human Services (HHS):

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. 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. 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. 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. 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.⁸⁹

In 2012, a group of fourteen disability advocacy organizations approached HHS and urged the agency to take action to end the practice of discrimination against individuals with disabilities being denied access to transplant lists after several notable cases involving individuals with disabilities, including children,

⁸⁸ Tien-Kha Tran, *Organ Transplantation Eligibility: Discrimination on the Basis of Cognitive Disability*, 24 J.L. & POL'Y 631, 635, 643 (2016).

⁸⁹ *Id.* at 638 (citations omitted).

experienced this discrimination.⁹⁰ In October 2016, a group of thirty U.S. Congress members petitioned the HHS Office of Civil Rights (OCR) in a letter urging the agency to provide federal legal guidance on this issue to ensure individuals with intellectual and developmental disabilities would not continue to be denied eligibility for placement on organ donation transplant lists solely on the basis of disability.⁹¹ Up until this point, HHS has failed to issue any federal legal guidance in this area despite the mounting pressure to take up the issue immediately.⁹²

Due to an unresponsive federal government, several states have passed or developed legislative efforts to ensure individuals with intellectual or developmental disabilities are not left completely off of waitlists or placed lower on waitlists due to their disabilities.⁹³ Several states have either recently passed legislation or have pending legislation on this issue.⁹⁴ The following states have passed laws prohibiting discrimination against people with disabilities in placement on organ donation transplant lists: California, Maryland, Massachusetts, New Jersey, Oregon, Delaware, Ohio, and Kansas.⁹⁵ Several states have pending legislation, which includes Washington and New York.⁹⁶ The Autistic Self Advocacy Network (ASAN) offers model legislation for states considering

⁹⁰ Michelle Diamant, *Advocates Call for End to Transplant Discrimination*, DISABILITY SCOOP (Sept. 21, 2012), <https://www.disabilityscoop.com/2012/09/21/advocates-end-transplant/16494>.

⁹¹ Letter from Mike Honda, Congressman & Jaime Herrera Beutler, Congresswoman to the HHS OCR (Oct. 12, 2016), <https://www.scribd.com/document/327914350/2016-10-12-Members-Letter-HHS-OCR-Organ-Transplant-Discrimination>. See also Michelle Diamant, *Disability No Reason to Deny Organ Transplants, Lawmakers Say*, DISABILITY SCOOP (Oct. 24, 2016), <https://www.disabilityscoop.com/2016/10/24/disability-organ-lawmakers/22920> (detailing contents of the letter).

⁹² See Bernstein, *supra* note 5.

⁹³ H.R. 332, 132nd Gen. Assemb. (Ohio 2017); Press Release, Ohio Gen. Assemb. H. of Reps., Rep. Antani Introduces Organ Transplant Waitlist Anti-Discrimination Bill (Aug. 31, 2017) (available at <http://dsaco.net/wp-content/uploads/non-discrimination-organ-donation-Press-Release.pdf>) [hereinafter Rep. Antani Press Release].

⁹⁴ See H.R. 332, *supra* note 93; Rep. Antani Press Release, *supra* note 93.

⁹⁵ NAT'L DOWN SYNDROME SOC'Y, *supra* note 87.

⁹⁶ See *id.*; Courtney Hansen, *Ending Organ Transplant Discrimination Against Kids with Disabilities*, MIGHTY (Feb. 16, 2018), <https://themighty.com/2018/02/organ-transplant-discrimination-kids-with-disabilities>; Kevin Landers, *Proposed Ohio Law Would Allow People with Disabilities to Receive a Transplant*, 10 TV WBNS (Feb. 4, 2018, 11:00 PM), <https://www.10tv.com/article/proposed-ohio-law-would-allow-people-disabilities-receive-transplant>.

enacting this anti-discrimination law.⁹⁷ Additionally, the National Down Syndrome Society (NDSS) offers a number of informational resources to assist states considering passing this type of anti-discrimination legislation.⁹⁸

III. QUALITY OF LIFE ASSESSMENT: ORGAN TRANSPLANT ELIGIBILITY & MEDICAL DECISION-MAKING

The first step in understanding how an individual can be denied placement on an organ donation waitlist requires understanding how the process operates procedurally. In February 2014, the Community Ethics Committee released a report on behalf of the Harvard Ethics Leadership Group, detailing the process by which organ transplant lists were created and exploring how criteria developed in making these decisions.⁹⁹ The report explains the federal legislation, the National Organ Transplant Act of 1984, which established the organ donation transplant process.¹⁰⁰

Organ transplants in the United States take place within a regulatory system created by the National Organ Transplant Act of 1984, which established the Organ Procurement and Transplantation Network (OPTN) operated under federal contract by the United Networks for Organ Sharing (UNOS), a private non-profit organization. The legislative intent in adopting a national transplant system was to create a system “for assuring equitable access by patients to organ transplantation and for assuring the equitable allocation of donated organs among transplant centers and among patients medically qualified for an organ transplant.” Congress sought to create a system in which “organs will be allocated according to objective standards of medical status and need” where there was “a reasonable likelihood of post-transplant survival.” In publishing the enabling legislation, the comments in the Federal Register specifically note that the transplant policies cannot violate the civil rights of candidates, but that federal oversight “should not micro-manage the development of purely medical

⁹⁷ AUTISTIC SELF ADVOCACY NETWORK, MODEL LEGISLATION: AN ACT CONCERNING NONDISCRIMINATION IN ACCESS TO ORGAN TRANSPLANTATION (2014), <http://autisticadvocacy.org/wp-content/uploads/2014/03/OrganTransplantationModelLegislation.pdf>.

⁹⁸ NAT'L DOWN SYNDROME SOC'Y, *supra* note 87.

⁹⁹ See generally COMMUNITY ETHICS COMMITTEE, *supra* note 7 (identifying and discussing the process for determining organ transplantation recipients and the allocation of organs among them).

¹⁰⁰ *Id.* at 2.

criteria or routine decision-making of attending medical professionals.¹⁰¹

Allocation of donated organs is determined by a facially-neutral computer program.¹⁰² However, the initial decision to place a patient on a recipient list is conducted by the transplant center, which considers an individual's psycho-social and other characteristics; thus, introducing subjectivity into the organ transplant process.¹⁰³

Patients seeking transplants enter the organ transplant process by referral to a transplant team at one of the organ transplant centers overseen by UNOS. The local transplant team determines whether to add the patient to the specific organ transplant list. UNOS operates the allocation system that matches available organs to patients once they are on the waiting list. Using a computer-generated matrix designed to prioritize a particular patient based upon geographic proximity, physical compatibility, and medical need, the UNOS allocation system does not factor in psycho-social or other unique characteristics of the Recipient Patient. That individual level of review occurs during the transplant center's decision whether to list the patient. Transplant centers are required to report in minute detail what happens to the patients on their respective waiting lists, including the number of transplant candidates, age, survival, and time on the list.¹⁰⁴

When medical professionals at the relevant transplant center scrutinize the candidate, things get murky in terms of criteria, which can differ vastly from center to center.¹⁰⁵ In a report for the Harvard Ethics Leadership Group, the Community Ethics Committee shed light on this dynamic.

Perhaps because of its impartial, computerized nature, the UNOS system for organ allocation has earned public trust. Nevertheless, the fact that each transplant center uses differ-

¹⁰¹ *Id.* (quoting Organ Procurement and Transplantation Network, 63 Fed. Reg. 16,296, 16,297, 16,304, 16,310 (Apr. 2, 1998) (codified at 42 C.F.R. § 121 (1991))).

¹⁰² *Id.* at 2–3.

¹⁰³ *Id.* at 2.

¹⁰⁴ *Id.*

¹⁰⁵ COMMUNITY ETHICS COMMITTEE, *supra* note 7, at 4.

ent, subjective criteria when making the decision to list a potential organ transplant recipient results in the understanding that organ transplant listing occurs in a black box, with undisclosed criteria and unreported decision-making.¹⁰⁶

UNOS provides the following steps for individuals who are seeking to be put on the national organ donation list:

1. Receive a referral from your physician.
2. Contact a transplant hospital. Learn as much as possible about the 200+ transplant hospitals in the United States and choose one based on your needs, including insurance, location, finances and support group availability.
3. Schedule an appointment for evaluation to determine if you are a good candidate for transplant.
4. During the evaluation, ask questions to learn as much as possible about that hospital and its transplant team.
5. The hospital's transplant team will decide whether you are a good transplant candidate. Each hospital has their own criteria for accepting candidates for transplant.
6. If the hospital's transplant team determines that you are a good transplant candidate, they will add you to the national waiting list.¹⁰⁷

A number of determinations must be made with regard to the candidate for organ transplant prior to the individual's placement on an organ donation transplant waitlist with the transplant center.¹⁰⁸ The candidate's primary care physician is instrumental in starting the actual process.¹⁰⁹

The Recipient Patient must be referred to the transplant center with an irreversible and otherwise fatal disease resulting in organ failure, while still being otherwise healthy enough to survive and benefit from an organ transplant and to comply with a life-long medication regimen. The Recipient Patient must meet strict medical criteria which include not

¹⁰⁶ *Id.* at 3.

¹⁰⁷ *Frequently Asked Questions*, UNITED NETWORK FOR ORGAN SHARING, <https://unos.org/transplantation/faqs/> (last visited Apr. 25, 2019) [hereinafter UNOS, *Frequently Asked Questions*] (select "how do I get on the waiting list?").

¹⁰⁸ *Id.*; COMMUNITY ETHICS COMMITTEE, *supra* note 7, at 3.

¹⁰⁹ COMMUNITY ETHICS COMMITTEE, *supra* note 7, at 3.

suffering from multiple organ failure, not wrestling with a persistent or pervasive infection, and not having any other treatment options available. In the case of a child, the entire process to obtain an organ transplant must be undertaken by a parent/surrogate who has the ability to advocate effectively for their child. In all events, the potential organ recipient is in dire need.

The network of a Recipient Patient's physicians and medical caregivers play a critical role in opening the doors necessary to proceed with an organ transplant. If the patient's primary care physician does not perceive a medical need or benefit, no referral to a specialist can occur. If the specialist makes a determination that a transplant is not a medical treatment option that will provide a likely benefit to the patient, no referral to a transplant center can occur. These highly discretionary decisions take place outside the system created by the federal transplant statutes and regulations.¹¹⁰

At the point that a candidate has passed the initial requisite stages of medical necessity and referral, the decision-making then shifts to the transplant center where a number of considerations may come into play as far as criteria for eligibility on the organ transplant donation list, such as

[w]hen a Recipient Patient has passed the scrutiny of their primary care physician and specialist, the transplant center must then decide whether an individual patient gains access to placement on the list which will entitle them to consideration for a transplant should an appropriate organ become available. The transplant center team evaluates the medical status of the patient and the medical and psycho-social factors that determine whether the recipient patient will survive a transplant and benefit from a transplanted organ. Because placement on the list is an absolute prerequisite to obtain an organ transplant and because it is essentially a non-appealable decision, the transplant team's determination carries life-saving significance and power. Basing that determination on medical criteria alone is challenging due to the constantly changing status of the patient, the prognostic uncertainties of the patient's condition, and the shifting balance created by the failure of one organ escalating the adverse effect to the patient's overall health and well-being. Adding psycho-social criteria to the

¹¹⁰ *Id.*

team's determination of eligibility for placement on the list is fraught with peril. At issue are such evaluative criteria as the patient's likely adherence to the strict, lifelong regimen of anti-rejection medicines; their ability to comply with follow-up medical appointments and sometimes invasive post-surgical interventions; the existence of support systems to assist with compliance; and their past history of drug abuse, mental health issues, and intellectual developmental disorders. Falling within the category of psycho-social criteria is the question of whether a potential recipient's quality of life will be enhanced enough to balance out the considerable rigors of both the organ transplant procedure and the intensive after-care required.¹¹¹

UNOS indicates that there can be a vast difference in standards and ultimately, a determination for eligibility on organ donation waitlist from one transplant center to another.¹¹² It describes this process as follows:

A transplant program must evaluate anyone who may wish to have a transplant, and it would make the final decision about whether to accept that person as a candidate. You are not automatically listed for a transplant just because you've had some contact with a transplant program.

Each transplant program makes its own decision about whether to accept someone for a transplant. The transplant team at each program has its own standards for accepting candidates. Each team may view the same facts and information different ways and make different decisions about listing a person for a transplant. So if one program is not willing to accept you as a candidate, a different program may accept you.¹¹³

The Harvard Ethics Leadership Group by the Community Ethics Committee pointed out that the individual with an intellectual or developmental disability can potentially be eliminated as a candidate for placement on an organ dona-

¹¹¹ *Id.*

¹¹² See UNOS, *Frequently Asked Questions*, *supra* note 107.

¹¹³ *Id.* (select "What do I need to do to be considered for a transplant?").

tion transplant list at very early stages in the process.¹¹⁴ An explanation of these denials was described by the Community Ethics Committee as follows:

Patients who suffer from intellectual developmental disorders are sometimes excluded from organ transplant lists even though a medical need is confirmed. The exclusion can occur at multiple points throughout the evaluation process - at the beginning, when a primary care physician does not make a referral to a specialist and, after that, when a specialist does not make a referral to a transplant center. Even when those first two hurdles are overcome, transplant teams sometimes make determinations not to list patients with intellectual developmental disorders based upon idiosyncratic and non-transparent psycho-social criteria. Using the rubric of psycho-social criteria, individuals with intellectual developmental disorders are sometimes seen as having extra difficulties complying with rigorous medical treatment regimens and as not receiving a true or sufficient benefit from the transplant based upon quality of life determinations.¹¹⁵

In reviewing whether an intellectual or developmental disability should be part of the criteria for eligibility on an organ donation transplant waitlist, the Harvard Ethics Leadership Group by the Community Ethics Committee acknowledged that a difficulty arises in defining “disability” in this context.¹¹⁶ The Community Ethics Committee took the following position in defining “disability”:

What distinguishes a disability from a disorder from a deficit from a dysfunction from a difficulty from a disease? What is neurological as opposed to cognitive or intellectual? The differences are often indistinct. In an effort to ensure we were using language that is grounded in professional scholarship and public accessibility, we went to both the World Health Organization’s International Classification of Diseases and Related Health Problems and the American Psychological Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM-5). Both showed wisdom in replacing the category of “mental retardation” with “intellectual developmental disorder.” Using “intellectual” over neurological or

¹¹⁴ COMMUNITY ETHICS COMMITTEE, *supra* note 7, at 4.

¹¹⁵ *Id.* at 4–5.

¹¹⁶ *Id.* at 12–13.

cognitive helps the discussion because it is widely used and understood—socially, scientifically, and politically—and transcends the use of IQ alone. The use of “developmental” introduces the context of brain development, taking into account the process and possibility of change. As the WHO International Classification of Functioning, Disability and Health Report of 2002 notes “every human being can experience a decrement in health and thereby experience some disability. This is not something that happens to only a minority of humanity.” We are all developing both health and disability. Use of the term “disorder” is key, meaning a “clinically recognizable set of symptoms or behavior” which is both flexible and capable of improvement. The Committee concluded use of the phrase “intellectual developmental disorder” is preferable to its alternatives and its use could help engender trust in the organ transplant listing process.¹¹⁷

The Stanford Encyclopedia of Philosophy has devoted study to the definition of disability and has made the following analysis in terms of how “disability” is viewed:

Two common features stand out in most official definitions of disability, such as those in the World Health Organization (2001; 1980), the U.N. Standard Rules on the Equalization of Opportunities for People with Disabilities, the Disability Discrimination Act (U.K.), and the Americans with Disabilities Act (U.S.) : (i) a physical or mental characteristic labeled or perceived as an impairment or dysfunction (in the remainder of this entry, we will refer to such characteristics as “impairments,” without assuming the objectivity or validity of that label) and (ii) some personal or social limitation associated with that impairment. The classification of a physical or mental variation as an impairment may be statistical, based on the average in some reference groups; biological, based on a theory of human functioning; or normative, based on a view of human flourishing. However classified, impairments are generally seen as *traits* of the individual that he or she cannot readily alter. Just what makes a condition a trait or attribute of an individual is obscure and debatable, but there seems to be agreement on clear cases. Thus, poverty is not seen as an impairment, however disabling it may be, nor is tasteless clothing, even if it is a manifestation of impaired fashion-sense rather than scarce income. On the other hand, diseases are

¹¹⁷ *Id.*

generally classified as impairments, even though they are rarely permanent or static conditions. Diseases that are not long-lasting, however, such as the flu and the measles, do not count as impairments.¹¹⁸

This Article will revisit the definition of “disability” in a later section to explain how the legal definition is framed for legal protections. For now, it is important to know that there are different ways to define “disability.” As the Harvard report shows, these different models significantly impact how an individual may be assessed for eligibility for an organ donation.¹¹⁹

Furthermore, it is important to emphasize how defining and discussing “disability” can change the scope of a policy. How disability is defined is essential to this very examination into questionable underlying policies, both written and unwritten, that form the criteria for organ donation transplant. Examining what “disability” entails is what ultimately arises in these decisions for organ donation transplant eligibility is a “quality of life” determination.¹²⁰ This “quality of life” assessment has often influenced health policy. Unfortunately, there is frequently a disconnect of knowledge between the individuals with disabilities and those in the arena of health policy making those decisions, or even worse, the disabled are completely disregarded when determining policies that directly impact them.¹²¹

Furthermore, physicians are able to use the “quality of life” assessment to mask when the disability is the *per se* reason for a determination of ineligibility to qualify for the organ donation transplant list. Such a “quality of life” determination is ultimately a value judgment being made on the life of the person with intellectual or developmental disability. In its report, the Harvard Ethics Leadership Group by the Community Ethics Committee disregarded the use of “quality of life” as a necessary criterion to determine eligibility on an organ donation transplant list.¹²² In explaining its rationale for disregarding the “quality of life” analysis, the Community Ethics Committee stated that:

¹¹⁸ David Wasserman et al., *Disability: Definitions, Models, Experience*, STAN. ENCYCLOPEDIA OF PHIL., <https://plato.stanford.edu/entries/disability/> (last revised May 23, 2016).

¹¹⁹ COMMUNITY ETHICS COMMITTEE, *supra* note 7, at 13.

¹²⁰ *See id.*

¹²¹ Wasserman et al., *supra* note 118.

¹²² COMMUNITY ETHICS COMMITTEE, *supra* note 7, at 13.

The addition of psycho-social criteria as a basis for an organ transplant listing decision makes definitional certainty absolutely imperative. Perhaps no phrase used in this area is more challenging than “Quality of Life,” impossible of measurement and, therefore, completely unusable as an organ transplant listing criteria. In wrestling with this topic, the Committee concluded that any determination of “quality of life” is the rightful domain of the Recipient Patient and their parents/caregivers to determine. It is clear that the intensity and commitment of parental supports provided to intellectually challenged children play a significant role in a Recipient Patient’s quality of life both pre- and post-transplant. Those outside that familial circle can provide advice and counsel, but deciding what constitutes quality of life is solely within the purview of the patient and parents/caregivers.¹²³

Therefore, not only do some individuals believe that “quality of life” does not belong in the criteria for determining eligibility of individuals to be on organ donation lists, but it also shows that the very concept itself is problematic because it is too difficult to define in any concrete way.¹²⁴

Harvard reviewed the various criteria transplant centers used and tried to apply them.¹²⁵ The Committee’s initial beliefs about this analysis were vastly different by the end of its study.¹²⁶ The Committee concluded the only criteria of value in making these eligibility determinations was strictly based on medical criteria.¹²⁷ The Committee made the following analysis:

The Committee began its review of this topic with a concern about rationing scarce resources – recognizing that a “public trust” was established upon the Donor’s gift of an organ. We spent time evaluating criteria for organ transplant listing based upon what kind of patient would receive the organ—would they be compliant with demanding medical regimens; would they obtain a sufficient medical benefit from the surgery; would their quality of life be enhanced? We were

¹²³ *Id.*

¹²⁴ *Id.*

¹²⁵ *Id.*

¹²⁶ *Id.*

¹²⁷ *Id.*

concerned that, if the organ went to a patient who was also afflicted with a severe intellectual developmental disorder, the public trust would be compromised—the gift was given with an assumption of its “highest and best use.” As we delved into the subject, however, our perspectives began to change. As we pushed and pulled, testing the criteria used for listing a particular patient, the only criteria that held validity in the end was medical necessity. No matter how many matrixes and grids were found, we concluded we could not judge someone else’s quality of life. The psycho-social criteria commonly used by a transplant center in making the organ transplant listing decision provided no solid ground on which to base such a weighty decision - equitable access and ethical confidence were not to be found outside solidly medical criteria.¹²⁸

The Committee concluded that although the listing process may seem standard in its application, the criteria used by transplant centers is vastly different from one center to the next.¹²⁹ It also determined there is no reason to exclude an individual with an intellectual or developmental disability from being listed simply based on the disability.¹³⁰ As the Committee reasoned:

As we have noted, the UNOS system of organ allocation has gained a measure of public trust. The discretionary nature of the organ transplant listing decision is largely unnoticed, however. The Committee concluded that all patients with medical need who would receive a sufficient medical benefit should be included in the opportunity to be listed for an organ transplant. Patients with intellectual developmental disorders should not be categorically excluded from that opportunity. The Committee understands that having the opportunity to be listed does not automatically result in being listed – medical criteria must still be applied and discretionary professional judgments must still be made.¹³¹

Despite the very clear suggestion by Harvard in 2014 that the criteria being used has significantly complicated and potentially jeopardized placement on organ donation lists for the intellectually and developmentally disabled, these

¹²⁸ COMMUNITY ETHICS COMMITTEE, *supra* note 7, at 13.

¹²⁹ *Id.* at 14.

¹³⁰ *Id.*

¹³¹ *Id.*

practices continued to be used across the country.¹³² Many states have responded by passing legislation in the form of anti-discrimination laws that not only ensure that individuals with disabilities are not excluded from organ transplant donation lists on the basis of their disabilities, but that they are not listed lower on waitlists because of disabilities.¹³³ This approach to legislation also directly challenges the use of quality of life assessment in the area of health care.

IV. SHIFTING THE PERSPECTIVE OF DISABILITY: THE MEDICAL MODEL V. THE SOCIAL MODEL—OR SOME COMBINATION?

The legislative trend of anti-discrimination laws being enacted by states to protect the right to access placement on organ transplant donation lists for those with intellectual or developmental disabilities frame the person with a disability in terms of human dignity and respect as opposed to a quality of life analysis. This shift is not traditionally seen in health care rights, even while there has been progress in other areas such as rights to education and employment.¹³⁴

For some time, the medical model of disability has dominated issues of health care access with regard to individuals with disabilities. The medical model views disability as follows:

The medical model is presented as viewing disability as a problem of the person, directly caused by disease, trauma, or other health condition which therefore requires sustained medical care provided in the form of individual treatment by professionals.

In the medical model, management of the disability is aimed at a "cure," or the individual's adjustment and behavioral change that would lead to an "almost-cure" or effective cure.¹³⁵

¹³² Ellen Stumbo, *After Being Denied, Person with Intellectual Disability Gets a Spot on the Transplant List*, MIGHTY (Feb. 18, 2019), <https://themighty.com/2019/02/intellectual-disability-denied-unos-organ-transplant-list>.

¹³³ NAT'L DOWN SYNDROME SOC'Y, *supra* note 87.

¹³⁴ See Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004); Rehabilitation Act of 1973, 29 U.S.C. §§ 701–753 (1973); Americans with Disabilities Act, 42 U.S.C. §§ 12101–12213 (1990).

¹³⁵ *Definitions of the Models of Disability*, *supra* note 11.

Contrary to this view, the social model of disability offers a much different approach to its view of disability. According to the social model:

The social model of disability sees the issue of "disability" as a socially created problem and a matter of the full integration of individuals into society.

In this model, disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment. Hence, the management of the problem requires social action and is the collective responsibility of society at large to make the environmental modifications necessary for the full participation of people with disabilities in all areas of social life.

The issue is both cultural and ideological, requiring individual, community, and large-scale social change. From this perspective, equal access for someone with an impairment/disability is a human rights issue of major concern.¹³⁶

Disability law scholars have even recognized that as these different understandings of disability have emerged between medical and social, the model or theory that has been incorporated into laws has not been consistent.

Disability is conceptually complex, incorporating social, legal, and medical aspects. Not surprisingly, the law has struggled regarding what qualifies as a disability and how to protect individuals within this large and diverse category. Given the increased need for health care faced by many individuals with disabilities, the law has at times framed "disability" as a medical designation. However, people with disabilities also face significant social barriers, which stem not from medical need but from stigma and stereotype. Consequently, the law has also defined "disability" in terms of the social experiences of exclusion, disadvantage, and discrimination. The result has been a substantive split between the health and civil rights protections for individuals with disabilities.¹³⁷

¹³⁶ *Id.*

¹³⁷ Jessica L. Roberts, *Health Law as Disability Rights Law*, 97 MINN. L. REV. 1963, 1967 (2013) (citations omitted).

A comprehensive explanation on the difference between medical and social models of disability and how they impact health and civil rights legislation is described below.

As explained, health law construes disability as a medical category. The disability rights movement, however, adopted a different position, known as the “social model” of disability. The social model recasts “disability” from a functional limitation to a limitation imposed by the interaction between a person’s impairment and her physical and social environment. [This “either-or” mentality resulted from a number of characteristics associated with health law.] Once disability is understood as a social problem, the focus shifts from the individual body of the person with a disability to the structural shortcomings of the society at large. The social model gives way to the civil rights model: construing disability as a social category lays the foundation for understanding people with disabilities as a minority group that has experienced discrimination and oppression. By advocating the social model of disability, those activists reframed the historical exclusion of people with disabilities from the result of functional limitations to an issue of civil rights.¹³⁸

However, the bans examined by this Article, illustrating how people with disabilities are discriminated against in the context of organ transplants, suggest that a change is permeating health care access now more than ever. However, this access to health care takes the form of legal protections through civil rights/anti-discrimination legislation that embraces the social model of disability.

Scrutiny of health law reveals it has fallen behind in championing health issues that affect people with disabilities. The earliest laws that advanced the rights of individuals with disabilities primarily fell within the social service arena, which were quickly replaced by protections through civil rights/anti-discrimination laws, and

[u]ntil the disability rights movement of the last forty years, disability legislation consisted almost exclusively of social welfare protections, some of which fall under the broad umbrella of health law. However, when disability rights advocates mobilized in the 1970s, they reframed the disadvantages faced by people with disabilities from personal, medical prob-

¹³⁸ *Id.* at 1982–83.

lems to the consequences of pervasive, society-wide stigma and discrimination. In promoting independence for individuals with disabilities, advocates renounced the charity-driven paternalism of the existing social-benefits system, resulting in a move toward antidiscrimination protections as the preferred means for accomplishing their goals.¹³⁹

This noted shift came as a result of the disability rights movement's desire to pursue the protection of the rights of individuals with disabilities from the perspective a medical condition that needs correcting to a social model that embraces changing the conditions of the environment to enable the person with a disability to flourish.

While accessing health care protections for people with disabilities has come through public health programs and civil rights laws, those have not always resulted in safeguarding those protections as they were intended to.¹⁴⁰ There have been numerous challenges to securing health care rights under traditional means; according to Professor Roberts, Director of the Health Law & Policy Institute at the University of Houston Law Center,

despite the groundswell of support within the disability rights movement, civil rights laws have failed to address the serious health disparities that the disability community faces. People with disabilities encounter numerous barriers to accessing health care. For instance, Medicaid and Medicare often fail to cover needed health services and medical equipment. Moreover, for individuals with disabilities who do not qualify for public programs, the risk assessment and cost-sharing practices of the private health-insurance industry frequently render them un- or under-insured. Finally, public health authorities have historically failed to compile information related to disability, making the extent of these disparities difficult to assess. Although both the Rehabilitation Act and the ADA facially apply in health-care settings, those statutes have been ineffective at targeting these inequities because of their civil rights structure. The statutes' vulnerability to restrictive court interpretations, coupled with their focus on

¹³⁹ *Id.* at 1965.

¹⁴⁰ *Id.*

individual instances of discrimination, make civil rights law an inappropriate tool for challenging health disparities.¹⁴¹

Despite the existence of protections under the ADA, such protections were determined to be too difficult to enforce with regard to organ transplant eligibility.¹⁴² This ineffectiveness of federal civil rights disability law led to the eventual passage of statutes at the state level to prevent discrimination based on disability in eligibility for organ transplant.¹⁴³ However, those state laws still take the form of the same anti-discrimination framework that has proven to be unworkable at the federal level. It has been suggested that this shift in treatment of disability and access to health care came about through health law, specifically through the Patient Protection and Affordable Care Act (ACA).¹⁴⁴ ACA has incorporated provisions that have embraced the social model of disability that was pushed through civil rights legislation into the health law arena.¹⁴⁵ As a health law, ACA opened the doors to health care access in a variety of ways that had previously been denied for people with disabilities and has made some believe that health law is now the best avenue for people with disabilities to secure legal protections to health care:

Quite intuitively, the solution to the inequities experienced by individuals with disabilities in health care appears to rest—not in civil rights law—but in health law. Both scholars and activists alike have proposed that the future of disability rights lies in protections traditionally associated with health legislation. The ACA makes that proposal a reality. The statute includes multiple provisions that both explicitly and implicitly benefit people with disabilities, including its attempted expansion of Medicaid and public health-insurance coverage for ongoing care, its elimination of preexisting condition exclusions and limitations on health status-based rating, and its recognition of people with disabilities as a health disparities group.¹⁴⁶

¹⁴¹ *Id.*

¹⁴² *See* Tran, *supra* note 88, at 649.

¹⁴³ *Id.*

¹⁴⁴ Roberts, *supra* note 137, at 1965.

¹⁴⁵ *Id.* at 1965–66.

¹⁴⁶ *Id.* at 1965.

Although bans on exclusion from organ transplant lists are framed in the traditional civil rights/anti-discrimination mold, they were created because such protections could not be sought through the established federal civil rights law for people with disabilities.¹⁴⁷ An example of this comes from trying to enforce rights to treatment under the ADA.

In the leading case on the subject, the Second Circuit held that the Rehabilitation Act does not apply to treatment decisions. Likewise, the ADA preserves a physician's ability to make treatment and other decisions, such as accepting or rejecting a patient, so long as she does not base her decision on the patient's disability. Justice Ginsburg, writing for the majority, further reiterated this point in a footnote in the 1999 Title II case, *Olmstead v. L.C. ex rel. Zimring*. She opined:

“We do not in this opinion hold that the ADA imposes on the States a ‘standard of care’ for whatever medical services they render, or that the ADA requires States to ‘provide a certain level of benefits to individuals with disabilities.’ We do hold, however, that States must adhere to the ADA’s nondiscrimination requirement with regard to the services they in fact provide.”¹⁴⁸

It has, therefore, been the position of the courts that civil rights laws, like the Rehabilitation Act and the ADA, do not ensure a basic level of medical care or benefits for people with disabilities, but rather protect individuals with disabilities from being treated differently than patients and beneficiaries without disabilities.¹⁴⁹ Unfortunately, this means that these laws may face the same challenges of enforcement as the ADA and other civil rights legislation. However, these laws provide access to health care and ultimately life, based on the principles of “access, integration, and equality” which have been championed for ACA’s success for people with disabilities’ access to health care.¹⁵⁰ If someone with an intellectual or developmental disability ends up being able to receive an organ transplant because he or she was not denied placement on a transplant list due to the protection afforded by a state’s anti-discrimination law, it seems the state’s anti-discrimination law mirrors the principles of “access, in-

¹⁴⁷ See Tran, *supra* note 88, at 659–60.

¹⁴⁸ Roberts, *supra* note 137, at 2005 (quoting *Olmstead v. L.C. ex rel. Zemring*, 527 U.S. 581, 603 n.14 (1999)).

¹⁴⁹ *Id.*

¹⁵⁰ *Id.* at 2021.

tegration, and equality” that are hallmarks of the protections provided by ACA as a major piece of health legislation.

V. CONCLUSION

Only time will tell what will happen with this legislation that demonstrates the continuing complexity of access to health care for individuals with intellectual and developmental disabilities, and whether such rights are more appropriately placed in civil rights/anti-discrimination or the health law context. This most recent example of anti-discrimination legislation to protect the rights of these individuals, giving them access to placement on organ transplant lists, points to an important victory for people with disabilities. Instead of defining a person with a disability solely by his or her medical conditions or limitations, this legislation goes against the traditional medical model and defines him or her as a human being with dignity that is deserving of every opportunity to have a full life in society that can be fundamentally altered by having access to health care protections. While this new model may not be completely abandoning the medical model, it does pay greater attention to recognizing the social barriers that people with disabilities must face in acquiring necessary access to critical health care, as seen through the example of organ transplant list eligibility. Further, this is being accomplished not by completely eliminating a consideration of quality of life, but rather, a simultaneous shift of focus to an acknowledgment that quality of life is a decision of individuals with disabilities and their families rather than those making medical decisions.

An important consideration and topic of tension is the correct avenue through which these laws should be implemented—civil rights/anti-discrimination law or health law. It is not enough for us to continue with tokens and platitudes of our desire to protect the rights of people with disabilities. There needs to be action beginning first and foremost with health care protections for the majority of the population. Thus, it is time that we view people with disabilities beyond their disabilities and view them as people equally deserving of access to health care and its protections. As difficult as it is to define “disability,” it is equally difficult to find the best place for those legal protections in health care that encompass both medical and social dynamics. States that have passed anti-discrimination laws in this instance demonstrate the necessary action that has been missing—giving people with intellectual and developmental disabilities the same chance to continue living as a non-disabled individual. Placement on an organ transplant list is not a guarantee of an organ. However, that action, in and of itself, is an important step in signaling the value of the life of the person with a disability. Maybe it ultimately does not matter what form the law takes as long as the law provides access to necessary health care and it is enforceable. For many individuals with intellectual and developmental disabilities across the country, it can mean the difference between life and death.