

Unequal Opportunity:
Transplant Denial for Patients with Intellectual Disabilities

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When a patient needs a transplant, a doctor must refer the patient to a waitlist prioritized by illness severity and duration on the list (UNOS, n.d.). The process matches organs to candidates who have the highest medical urgency; distance, blood type, and organ size are also considered. A doctor, however, makes the final decision, taking into account other medical and non-medical factors. However, some of these factors may introduce bias into the decision-making process, leading to discrimination. In the United States, about 13 percent of donated organs are never matched to a patient and are therefore discarded (Israni et al., 2020). Nevertheless, some doctors have withheld available organs from intellectually disabled patients with end-stage organ disease, doubting that they can maintain post-transplant regimens (Wightman et al., 2018). Disability may also be cited to justify low estimates of patients' expected post-transplant quality and duration of life.

In the absence of definitive standards of care in such cases, physicians can and do exercise broad discretion. This raises the question of how advocates have pushed for equal consideration of organ transplants for candidates with intellectual disabilities. Patients and disability advocacies have reduced discrimination in organ assignment against people with intellectual disabilities through public education, publicity, and policy recommendations, opposing physicians' utilitarian reasoning with a rhetoric of human dignity, equality, and rights.

Literature Review

Thammana et al. (2013) found evidence of racial or socioeconomic status disparities in transplant referrals in the U.S. For nonwhite children, waitlist referral times for liver transplantation were longer than those for white children. Black individuals with end stage kidney disease were 55 percent less likely to receive a kidney transplant than white individuals

along with an 18 percent lower likelihood to be included on the transplant wait list (Sawinski et al., 2022). Through machine learning modeling, Wadhvani et al. (2019) found that post-transplant outcomes were worse for nonwhite recipients than for patients generally, perhaps due to greater delays. Racial disparities in organ transplants have been more widely studied than disparities associated with disability, for which accessible data are relatively scarce. Efforts to redress racial disparities may be applicable to disparities of other kinds, including those associated with disability. Efforts to mitigate racial disparities in organ transplantation include educational programs for practitioners (Mohottige et al., 2021). Mohottige et al. also recommend programs to promote equity in referral policies. To achieve a small reduction in racial disparities in transplant referrals, the Emory Transplant Center in Georgia modified policies and introduced educational programs (Pullen, 2018). Similar efforts may diminish discrimination in transplant approvals for disabled patients.

Research findings have refuted typical reasons for denying transplants for disabled patients. It is not uncommon for doctors to consider intellectual disability as a factor in transplant decision-making. Richards et al. (2009) found that 43 percent of programs consider intellectual disability in the listing process. Richards also found that 25 percent of programs explicitly would not refer a patient with severe intellectual disability to the transplant waitlist. Wall et al. (2020), reaching a similar conclusion, found that 24 percent of organ transplant programs consider severe intellectual disability a contraindication in waitlist referrals. In making a transplant referral decision for a disabled patient, doctors prioritize post-transplant outcomes, including life expectancy. However, there is no statistical difference between patients with Down syndrome and other patients in post-transplant outcomes following pediatric heart transplants. Godown et al. (2022) conclude that because intellectual disabilities are irrelevant to such outcomes, they

should not be a factor in transplant decision-making. Since people with intellectual disabilities typically have shorter lifespans, doctors' assumptions about disabled patients' life expectancy may also affect transplant decisions. Following transplants, however, short-term and long-term survival rates among patients with and without disabilities are similar (Wightman et al., 2021).

Public Education

The Organ Procurement and Transplantation Network (OPTN) connects donor organs to potential recipients in the U.S. while also providing guidance to organ procurement organizations and transplant centers. Led by doctors in transplant fields, OPTN publicly states that it's "unacceptable to use variations in transplant outcomes among social groups as a basis for predicting individual outcomes" even if a particular group has lower survival rates (OPTN, 2015). This can be extended to patients with intellectual disabilities, whom are believed to have poor post-transplant outcomes despite research proving otherwise. Though this public group of doctors discourages discrimination, they still have not enforced any policies for disabilities specifically. Additionally, their recommendations for organ allocation do say that factors may include "financial and social support, patient adherence" which goes against their own words that outcomes for certain social groups should not be a factor in decision making (OPTN, 2015). Given their influence over transplant entities, the doctors leading OPTN have the potential to significantly change the way organizations consider disability as a factor in transplant decision-making.

Thus, disability advocacies must still strive to reduce transplant discrimination through methods such as publicity campaigns. Nonprofit advocacies such as the Autistic Self Advocacy Network (ASAN) bring awareness to inequality in disability rights through educating people

involved in transplantation. While their focus as an organization is broader, they have informative resources on transplant inequality for many groups, including advocates and clinicians (ASAN, 2013b). They educate doctors primarily by providing facts on the success of transplants for disabled patients, as well as emphasizing the importance of a disabled person's support network. If a clinician is concerned with the notion that disabled individuals may not be able to maintain post-operational regimens, ASAN encourages the clinician to look at the individual's case rather than the clinician's biases about their disability. They should consider "all present and future supports available to the individual, whether the individual has a history of success at managing his or her treatment using existing supports; and whether additional supports available to the individual could improve the individual's ability to manage his or her treatment" (ASAN, 2013b). Clinicians should also be cognizant of their own biases when using quality of life as a factor in decision-making, as "clinicians' estimates may, as a result of their own 'horror of handicap,' dramatically undervalue the actual quality of life of disabled patients" (ASAN, 2013b). Rather, clinicians should redirect their focus to their patient's quality of health, not their own ideas of the patient's quality of life.

ASAN also provides a guide for advocates passionate about disability rights to "help dispel myths about people with disabilities who need organ transplants and promote policies that protect the right to lifesaving care" (ASAN, 2013a). The first crucial step is to simply educate oneself on the facts of existing legislature and research on organ transplants for disabled individuals; for example, people should know that post-transplant outcomes do not differ for people with and without disabilities. Intellectually disabled transplant candidates, especially children, may simply need a stronger support system for post-operative care to achieve this, either from a medical facility or from family and friends. Advocates may also help to educate

doctors, who may not seek out the resources provided by ASAN on their own. By reaching out to practices to inquire of the existence of anti-discriminatory policies, advocates can help to encourage policymaking in its absence. A simple method to achieve this is to refer to ASAN's "Organ Transplant for People with Disabilities: A Guide for Clinicians." By educating the public and clinicians, advocates can help to spread awareness for an issue infrequently discussed.

Spreading awareness

In 1996, Sandra Jensen was the patient in the first widely publicized case of a person with an intellectual disability receiving a major organ transplant. Jensen passionately advocated for disability rights, even attending President Bush's signing of the Americans with Disabilities Act in 1990 (Gay Stolberg, 1998). After her cardiologist recommended a heart-lung transplant considering her declining health, the two transplant teams she applied to rejected her because of her disability. Her lawyer, Michael Kluck, believed that this was unlawful and discriminatory under the Rehabilitation Act of 1973, which prohibits disability-based discrimination for federally funded organizations (Fremon, 1996). The transplant team at Stanford University Medical Center eventually changed their minds after the public and legal pressure. In a later interview, Dr. Theodore, who initially denied Jensen a spot on the waitlist, admitted, "We rejected her out of hand, based on a label ... That was wrong, and I'm willing to admit that" (Gay Stolberg, 1998). Shortly after her case, California amended its Health and Safety Code to include protections for disabled people within the context of organ transplants (California Code Health and Safety Code, 1996).

Jensen's story set the foundation for future cases of organ transplants for patients with disabilities as the first known disabled patient in the U.S. to receive a heart-lung transplant. The

publicity of the case educated doctors on the potential success of this kind of surgery and gave hope to disabled individuals in similar situations. Another young girl with Down Syndrome, Jodi Riddle, was also recommended a heart transplant by doctors because of a congenital heart condition. Her cardiologist did not agree. Her family was upset and angered by her cardiologist's claim that "she wasn't a productive person" because of her disability, and thus did not have a place on the waitlist (Noah, 1997). Her mother, Debra Stinson, knew of Jensen's success in pleading her own case and in the operation itself. She reached out to Kluk in hopes he could help Riddle the way he did for Jensen. Kluk helped the family write a letter to Riddle's cardiologist to educate him on disability discrimination laws, and the success in Jensen's case. This was successful, and Riddle was the second person with Down syndrome to be listed for an organ transplant.

For those who fully cannot yet speak for themselves, family members must advocate on their behalf. Chrissy Rivera, a mother of a three-year-old girl with Wolf-Hirschhorn syndrome, made a significant impact in her emotional blog post, "Brick Walls," by bringing to light the discrimination her daughter faced at the Children's Hospital of Philadelphia (CHOP). The doctor denied her daughter, Amelia, a kidney transplant, claiming "she is not eligible because of her quality of life because of her mental delays" despite Rivera's offer to donate her own kidney to her daughter, who had been denied a place on the waitlist (Rivera, 2012). He proceeds to explicitly say that he does "not recommend [the child] for a transplant because she is mentally retarded" and for no other medical reason. Rivera ends by hoping readers are "disturbed, troubled, distressed, and pissed off" from her story; she was correct.

This was met with public outcry and attention from multiple large media outlets, drawing criticism to CHOP. Over 50,000 people signed a petition to convince CHOP to allow Amelia to

receive a kidney transplant (Stilwell, 2012). Signers of the petition describe the hospital staff's actions as "utterly disgusting" and "despicable." CHOP posted a statement on their Facebook page, eliciting both supporting and criticizing comments (Children's Hospital of Philadelphia, 2012b). People defending the reputation of CHOP commented about their own stories of the wonderful care their family members had received by the staff, but seldom defended the staff's reasoning against a transplant for Amelia. Those speaking against CHOP, however, do not question their quality of care but rather discuss this specific incident. One commenter, Jolene Rose Powell, questioned the "ethics and rationale they are using to deny a patient a life saving operation" (Children's Hospital of Philadelphia, 2012b). Large media outlets, including as CBS (Loeb & Stahl, 2012), Fox News (*Disabled Girl Denied Kidney Transplant*, 2016), and ABC News (Donaldson James, 2012), reported on the events and garnered even more attention for the story. Shortly after, CHOP released an official statement that they are "completely committed to the careful review of [their] processes" concerning disabilities and transplantation (Children's Hospital of Philadelphia, 2012a). In a later blog post, Rivera shares that she was able to donate her kidney after Amelia was approved for a transplant that summer, ending with a successful surgery and recovery (Rivera, 2013). The negative media attention from Rivera's story exposing the blunt words of the doctor forced the hospital to review their transplant procedures.

In the same year Amelia was denied candidacy for a liver transplant, Charlotte Woodward, a woman with down syndrome, received her own life-saving heart transplant. She dedicated her time since to passionately advocate for others in similar situations through a mix of spreading awareness and lobbying for non-discriminatory legislature (Norlian, 2021). Woodward (2022) preaches that "there is no justice in excluding people with disabilities from society and that includes within the medical field." She widely advocates for all aspects of disability

equality, beyond transplant discrimination. TikTok, an increasingly popular video-based social media, is her primary method of choice for spreading awareness. She brings to light factors such as the wage gap for disabled individuals and the reduction of benefits when a disabled individual gets married. In 2020, Woodward got involved with Virginia lawmaking. She made a speech to the assembly about her own experience with organ transplants and the discrimination that others with disabilities had faced. With her help, Virginia passed a bill prohibiting organizations from refusing a person a place on the transplant waitlist because of their disability alone (Code of Virginia, 2020). After her success in Virginia, she began lobbying for in the U.S. Congress to pass a federal antidiscrimination law. Jensen, Rivera, and Woodward helped the public to learn about the discrimination disabled individuals face in the organ transplantation process, while also impacting policies from an organizational to a governmental level.

Policy approach

Section 504 of the Americans with Disabilities Act (ADA) prohibits discrimination against individuals with disabilities in programs and activities that receive federal financial assistance (American with Disabilities Act, 1990). The United Network for Organ Sharing (UNOS) governs the transplant waitlist, and while it is a private organization, is overseen by the federal government thus is subject to section 504 of the ADA. UNOS's guidelines are compliant with the ADA, but do not explicitly prohibit discrimination for listing based on disability (Romano, 2019). Members of UNOS have spoken as to their personal stance. Dr. Nicholas Halasz, chairman of the ethics committee of UNOS in 1996, states that "so long as you have a living, feeling human being, whatever level that individual functions at; that is still a living, feeling human being and needs to be considered" regarding organ transplants (Goldberg, 1996).

However, “the degree to which... [the] guidelines is followed by transplant centers or OPOs is unknown” (Romano, 2019). Policies set by organizations such as UNOS/OPTN may not be followed, but still would set an positive example for other transplant organizations to follow.

The National Council on Disability (NCD), an independent federal agency, promotes non-discriminatory transplant processes through extensive policy recommendations at all governing levels of transplantation. Considering the lack of clarity of UNOS/OPTN guidelines, the NCD suggests “to reform any UNOS/OPTN guidelines that could be interpreted by organ transplant centers as allowing people with disabilities to be kept off of the waitlist for a transplant” (Romano, 2019). Without clear language for considering disabilities in the transplantation process, these organizations unintentionally allow bias from transplant organizations and clinicians.

The council also provides analysis of the effectiveness of the existing ADA regulations regarding transplants. While the ADA prohibits discrimination, it’s unlikely to be enforced due to the urgency of transplants and the lack of language specifically addressing organ transplants. The council encourages the Department of Justice to “make clear that the ADA and Section 504 apply throughout the organ transplant process, including informal eligibility determinations, such that disability should only be taken into account to the extent that it can be clearly shown to be likely to impair successful transplantation” (Romano, 2019). They also suggest litigation at the federal level to explicitly prohibit transplant discrimination, following examples of states with existing policies.

As of 2022, there are 36 states with nondiscrimination laws for organ transplants (NDSS, 2022). In 1996, immediately following Jensen’s case, California was the first state in the United States to pass a law explicitly prohibiting disability discrimination for transplants. When it was

first introduced into the state government, the bill proclaimed 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” (California Code Health and Safety Code, 1996). Seventeen years passed before another state, New Jersey, enacted its own antidiscrimination laws. While Rivera’s case was with the Children’s Hospital of Philadelphia, they are New Jersey residents, leading to the state’s bill being introduced and passed the following year. The language of the bill provides protections for disabled patients, stating “New Jersey residents in need of organ transplants are entitled to assurances that they will not encounter discrimination on the basis of a disability” (NJ Rev Stat, 2013). As for the transplant centers themselves, this law now requires organizations “to use patient selection criteria that result in a fair and non-discriminatory distribution of organs” (NJ Rev Stat, 2013). Many other states passed similar laws in the years following New Jersey’s bill. Notably, Virginia’s antidiscrimination law passed with the help of disability advocate Charlotte Woodward. It prohibits denial of all transplant related procedures for disabled individuals, including “referral to a transplant center or specialist; inclusion on [a] ... transplantation waiting list; evaluation; surgery and related health care services; counseling; or post-transplantation treatment and services related to ... transplantation” (Code of Virginia, 2020). Nearly two thirds of the states with nondiscrimination legislature, including Virginia, passed their bills during or after 2020, indicating a quickly progressing positive trend for advocates’ state-level efforts.

However, action must be taken at a federal level in order to ensure no transplant discrimination may occur nationwide. After being introduced in the House by Representatives Jamie Herrera-Beutler and Katie Porter, the Charlotte Woodward Organ Transplant Discrimination Prevention Act was introduced to the Senate in December 2021 by Senator

Marco Rubio. It forbids clinicians and organizations from denying transplant services to individuals “solely on the basis of a qualified individual’s mental or physical disability” (Woodward Act, 2021). This includes all stages of transplantation, requiring equal consideration on the waitlist for disabled individuals and prohibiting refusal of transplant procedures based on disability alone. It has gathered support from the NCD, which encourages anti-discriminatory federal legislation for transplant services. Andrés J. Gallegos, chairman, praises the bill’s introduction, as it’s “type of legislation [they] recommended in [their] 2019 report” (Gallegos, 2021). The bill is also supported by the National Downe Syndrome Society, which Woodward has worked with extensively to help fight for disability rights (NDSS, 2022). While the bill has yet to be passed, this shows advocates’ actions have successfully made impact at all levels of governmental lawmaking.

Conclusion

Despite lack of sound statistical evidence for excluding patients with disabilities from organ transplantation, groups must still fight for equal consideration by ultimately bringing awareness to the issue to change transplantation policies. Disability bias in organ transplantation is not a widely discussed issue, and many clinicians may have preconceived biases. From criticizing individual programs to involving formerly uninvolved politicians, public attention draws support to those affected and encourages policy change to ban transplant discrimination. Considering the importance of public perception and reputation, programs are forced to reevaluate their approaches for disabled patients needing transplants when met with scrutiny. Jensen’s case helped another individual realize she could still fight for a transplant despite her cardiologist’s initial denial. Further, she, along with Rivera and Woodward, were direct causes of

anti-discriminatory state legislation, leading a cascade of other states passing their own laws in recent years. These state-level laws being passed proves that the social action taken by advocates is effective in enacting policy-based change. Woodward takes it further by lobbying in Congress for a federal change to finally be made. While measures undoubtedly must still be taken to reach true equality in organ transplant consideration, the methods used by disability rights advocates have been successful.

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