

Recommendations to Increase Access in Organ Transplantation for People with Disabilities

September 2022



CENTER FOR
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Recommendations to Increase Access in Organ Transplantation

Introduction

People with disabilities are denied access to organ transplants by not being added to transplant lists or facing longer wait times, despite needing organs to survive and meeting the criteria for transplant. These barriers to equitable access to life-saving organs are characterized by implicit bias, explicit discrimination, and a lack of access to reasonable accommodations. The problem is pervasive, but difficult to address due to the lack of transparency in the organ allocation process. This inequity can only be fixed by the medical profession becoming aware of their own implicit bias and changing their policies and practices.

To better understand where inequities lie for people with disabilities within the organ transplant allocation system, The Center for Dignity in Healthcare for People with Disabilities conducted a gap analysis. A gap analysis is a tool that is used to help investigate and create a plan to fix a problem or issue, utilizing a 4-step process in which one identifies the current state of an issue, identifies the ideal future state, finds the gaps between the two and then creates a plan to close those gaps. We have created the below recommendations as a result of our findings in the gap analysis and as a tool to close the gap in the systemic inequality for people with disabilities in organ transplant allocation.

Many of our recommendations are grounded in the The Americans with Disabilities Act of 1990¹ (ADA), a federal law intended to remove societal barriers and discrimination that persist in many areas, including health services. The ADA and related laws require organ transplant centers and physicians to make reasonable accommodations including modifications in their policies, practices, and procedures for individuals with disabilities seeking transplantation. Our gap analysis found that accommodations are not always provided satisfactorily. We have therefore proposed recommendations for improving the organ transplantation process that are based in this analysis.

¹ Americans With Disabilities Act of 1990. Public Law 101-336. 108th Congress, 2nd session (July 26, 1990).

Transparency and Oversight of Selection Criteria for Organ Allocation

Organ transplant centers should, whenever possible, consult with people with disabilities, their family members, and other stakeholders such as UNOS² when developing selection criteria. Stakeholders can provide suggestions unique to their specific needs and demographics, and are more aware of what it is like to live with a disability. Additionally, UNOS/OPTN³ have produced several non-binding guidance documents on the ethical allocation of organs that should be considered.⁴

Whenever possible, selection criteria should be written down and be publicly available on the organ transplant center's website. Historically, the lack of transparency in how organ transplant centers determine which patients will be recommended to the national waiting lists has resulted in transplant centers having either discriminatory policies, or vague, informal policies that may be prone to bias.⁵ Where a transplant center does have a formal policy, it may not be publicly available. To the extent possible, publicly providing selection criteria, resolves these issues.⁶

Person-Centered Planning and Supported Decision-Making

In healthcare, shared decision-making is accomplished jointly between the provider and the individual receiving care (and/or family caregiver if applicable.) This is key for patient/family centered care in which collaboration results in informed choices and optimal outcomes.

² UNOS- United Network for Organ Sharing (See Figure 1)

³ OPTN - The Organ Procurement and Transplantation Network is a public-private partnership that links all professionals involved in the U.S. in the organ transplantation and donation system. "UNOS was awarded the initial OPTN contract on September 30, 1986, and continues to administer the OPTN." *About, Organ Procurement and Transplantation Network*, <https://optn.transplant.hrsa.gov/about/>. (Last Accessed August 16, 2022).

⁴ *Ethical Principles in the Allocation of Human Organs*, Organ Procurement and Transplantation Network, <https://optn.transplant.hrsa.gov/resources/ethics/ethical-principles-in-the-allocation-of-human-organs> (Last Updated Jun. 2015).

⁵ See Nat'l Council on Disability at 31-33 ("A 2009 study of pediatric transplant centers stated that 69 percent of those surveyed reported that their transplant center's process for evaluating the relevance of neurodevelopmental disability to eligibility for an organ transplant, on a scale of 1 to 5, was mostly 'informal, implicit, or unstated' as opposed to 'formal, explicit, and uniform'...").

⁶ The Center for Dignity recognizes that the organ procurement and transportation network may be confusing and we have included an explanatory figure at the end of our recommendations. (See Figure 1).

One form of shared decision-making is person-centered planning. Person-centered planning is a strengths-based approach that “results in decisions, goals, and outcomes that are more targeted, relevant, and specific to the...” individual.⁷ The person’s individual goals, desires, and outcomes are given primary consideration in person-centered planning. They may be developed by a circle of interested supporters (including the person) and conveyed concretely in a person-centered plan. Person-centered planning, as well as consultation with the person with a disability and their supporters, should occur regardless of the legal decision-maker.

Clinical care providers and other providers who may be present during the medical decision-making process (such as social workers) must, however, establish who has the legal authority to make medical decisions. Sometimes this is the person’s guardian, who has legal authority to make decisions for them (typically a person with a disability), in a legal arrangement called guardianship. Guardianship, however, takes away legal rights from the person with a disability and is often not necessary for decision-making. It should be used very sparingly.

Supported decision-making is an alternative to guardianship. In supported decision-making, an individual with a disability makes their own choices with the assistance of a support person or group of support people. This aligns with the concept of self-advocacy/self-determination and the person-centered approach. While individuals with disabilities may make decisions differently than people without disabilities, they *can* make their own choices with support. Guardianship takes away an individual’s rights; therefore, The National Resource Center for Supported Decision-Making recommends this framework as an alternative to guardianship.⁸ In this framework, a person with disabilities who arrives for treatment with supporters typically does not have a guardian but is themselves the person who has the legal capacity to make medical decisions. In these situations, providers should allow the person’s supporters to accompany them to medical appointments but should be aware that the person with a disability retains the ability to make all decisions.

This ties directly into considerations regarding accommodations in the transplant decision process and post-transplant care plan. The transplant medication regimen and monitoring is complicated for anyone, and individuals with disabilities can comply with it

⁷ State of New Jersey Department of Education. Learning Opportunities: Person Centered Approaches in Schools and Transition (PCAST). (Last Accessed June 15, 2022). <https://www.state.nj.us/education/specialed/transition/person.shtml#1>

⁸ National Center for Supported Decision-Making. *Autonomy, Decision-Making Supports, and Guardianship*. Sunday, April 10, 2016. <http://www.supporteddecisionmaking.org/news/autonomy-decision-making-supports-and-guardianship>

with appropriate supports in place. Such supports might include, technology such as medication alarms, the mymedschedule app that shows when to take which meds, and pill organizers all go a long way towards preventing medication administration errors, which are the largest cause of preventable re-hospitalizations. These adjustments can be made easily by the person with access to supporters and with appropriate supports in place, as developed in a person-centered plan.

Home and Community Based Services (HCBS) available to individuals with I/DD could also improve medication administration. Supported decision-making and person-centered planning should incorporate and use HCBS to further the patient's goals. Further, training by hospitals prior to discharge for individuals (and family caregivers) on post-operative care such as how to take daily vitals, like blood pressure, when to call the doctor, etc. leads to increased transplant success.

Disability and Diagnosis Related Criteria for Transplantation

According to The National Council on Disability, “subjective judgments about the quality of life of people with disabilities, made by medical professionals without the input of their patients, have no place in medical decisions. Such judgments often are that people with disabilities, by virtue of being disabled, have a lower quality of life, and that belief, in turn, results in undervaluing their lives.”⁹ Nonetheless discriminatory psychosocial criteria, such as having a mental disability, are used regularly to screen out people with disabilities from transplantation.¹⁰

Organ transplant centers and physicians must assess candidates for organ transplants individually, and without relying on stereotypes about disability reducing quality of life or their ability to comply with post-transplant care regimens. The ADA requires individualized consideration of disability, meaning people with disabilities cannot be denied health care services or access to treatments before they have received an individualized assessment of their condition. Decisions concerning whether an individual is a candidate for treatment should be based on individualized assessments of the person, using current objective medical evidence, and not based on generalized assumptions about a person's disability. This includes an individualized assessment into the person's ability to comply with post-operative procedures, with access to supports such as direct caregivers or other social supports if needed. Any expectation that an

⁹ National Council on Disability, Organ Transplant Discrimination Against People with Disabilities 53-55 (Sept. 25, 2019), available at https://ncd.gov/sites/default/files/NCD_Organ_Transplant_508.pdf.

¹⁰ National Council on Disability. NCD Letter to HHS and DOJ on Organ Transplants. September 25, 2019. <https://ncd.gov/publications/2019/ncd-letter-hhs-and-doj-organ-transplants>

individual does so *independently* (i.e. without supports), would disregard the ADA's requirements for reasonable modifications.¹¹

Transplant surgeons may continue to make the case that an individual with I/DD may struggle to adhere to their necessary pre- and post-operative medical regimen. The postoperative transplant regimen is onerous immediately after surgery and requires a lifetime of medications and follow-up appointments. However, the ADA's requirement to provide reasonable accommodations means that patients with a disability can not be required to administer their post-op medical regimen *independently*. Since people with I/DD are often capable of adhering to medical regimens when they have access to supports, such as direct caregivers, auxiliary aids and services, and other social supports, these supports must be considered when making organ allocation decisions. Demanding that a person with an I/DD independently adhere to a medical regimen, when they could do so with supports, perpetuates unfair social systems that the ADA was built to combat.

There is mounting evidence that persons with I/DD benefit substantially from transplantation. Studies have found that there is no significant difference in short- and long-term mortality rates or graft survival for people with I/DD¹² and both individuals and their caregivers report improved quality of life after transplantation.¹³ Disability should only be considered to the extent it can be *clearly shown* through an individualized assessment and objective medical evidence to be likely to impair successful transplantation. Given the mounting evidence to the contrary, these instances should be very rare exceptions, and physicians should check their own implicit biases in this process to avoid unintentional discrimination or application of stereotypes. When in doubt, physicians should confer with a colleague with knowledge

¹¹ For additional guidance regarding clinical assessment of people with I/DD, see:

https://autisticadvocacy.org/wp-content/uploads/2014/03/OrganTransplantationClinicianGuide_final.pdf

¹² Martens MA, Jones L, Reiss S. Organ transplantation, organ donation and mental retardation. *Pediatr Transplant.* 2006;10(6):658-64; Goel A, Iyengar I, Schowengerdt K, Fiore A, Huddleston C. Heart transplantation in children with intellectual disability: an analysis of the UNOS database. *Pediatr Transplant.* 2016;21:e12858; doi: [10.1111/petr.12858](https://doi.org/10.1111/petr.12858); Wightman A, Bartlett HL, Zhao Q, Smith JM. Prevalence and outcomes of heart transplantation in children with intellectual disability. *Pediatr Transplant.* 2017; 21: <https://doi.org/10.1111/petr.12839>; Wightman A, Hsu E, Zhao Q, Smith J. Prevalence and outcomes of liver transplantation in children with intellectual disability. *J Pediatr Gastroenterol Nutr.* 2016;62:808- 812; Wightman A, Young B, Bradford M, et al. Prevalence and outcomes of renal transplantation in children with intellectual disability. *Pediatr Transplant.* 2014; 18: 714-719. Galante NZ, Dib GA, Medina-Pestana JO. Severe intellectual disability does not preclude renal transplantation. *Nephro Dial Transplant.* 2010; 25: 2753–7; Samelson-Jones E, Mancini DM, Shapiro PA. Cardiac transplantation in adult patients with mental retardation: Do outcomes support consensus guidelines? *Psychosomatics* 2012;53:133 –8.

¹³ Ohta T, Motoyama O, Takahashi K, et al. Kidney transplantation in pediatric recipients with mental retardation: Clinical results of a multicenter experience in Japan” *Am J Kidney Dis.* 2006;47(3):518-27.]

of the I/DD in question.

The National Council on Disability reported its findings and recommendations on this set of topics in the [“Organ Transplant Discrimination in People with Disabilities”](#) bioethics series. However, as recently as 2021, the Organ Procurement and Transplantation Network (OPTN) published a white paper, “General Considerations in Assessment for Transplant Candidacy” that fails to address the concerns the disability community has about discrimination in organ allocation.¹⁴

Data

While there are a substantial number of cases of disability bias in the allocation of organs that have been litigated, reported in the media, and sometimes even served as the basis of policy changes, there is a great need for additional data about when and how such bias affects allocation. For example, explicit disability bias sometimes appears in organ transplant policies that deprioritize or even preclude providing organs to people with certain disability diagnoses. However, these policies are not centralized and often not transparent, so it has been difficult to conduct a systematic study showing how many of these policies explicitly discriminate against people with disabilities and in exactly what ways. The data that would be produced by such a study would be enormously helpful for developing large scale anti-discrimination public policy in this area.

Likewise, given what we know about the presence of implicit bias against people with disabilities in medicine,¹⁵ there is strong reason to suspect that there is widespread implicit bias that disadvantages people with disabilities when they seek organ transplants. There has yet to be a large-scale study that documents the prevalence of these kinds of attitudinal barriers to accessing organs. Data that show patterns of implicit bias against people with disabilities present in those making allocation decisions would justify further interventions and help tailor those interventions to alter the particular attitudes and beliefs that present the greatest challenge to equity for people with disabilities.

¹⁴ Eric Messick. White Paper: General Considerations in Assessment for Transplant Candidacy. OPTN Ethics Committee. June 14, 2021.

https://optn.transplant.hrsa.gov/media/4640/wp_addressing_gen_considerations_for_tx_candidacy.pdf

¹⁵ Iezzoni, et al. "Physicians' Perceptions of People with Disability and Their Health Care."
<https://doi.org/10.1377/hlthaff.2020.01452>

Conclusion

We urge health care professionals to address this health disparity and end discrimination against people with disabilities in organ transplantation. The Center for Dignity in Healthcare for Disabilities is available to serve as a resource and partner to help you and your colleagues implement these recommendations.

Figure 1.

