



*Saving and improving lives with transplantation.*

**American Society of Transplant Surgeons®**

November 5, 2023

Xavier Becerra, Secretary  
Department of Health and Human Services  
Hubert H. Humphrey Building  
200 Independence Avenue, SW  
Washington, DC 20201  
*Submitted via regulations.gov*

Re: 45 CFR Part 84 RIN 0945-AA15; Discrimination on the Basis of Disability in Health and Human Service Programs or Activities (Disability Discrimination Proposed Rule or the Proposed Rule)

Dear Secretary Becerra:

The American Society of Transplant Surgeons (ASTS) is pleased to have the opportunity to comment on the Disability Discrimination Proposed Rule. ASTS is a medical specialty society representing approximately 2,000 professionals dedicated to excellence in transplantation surgery. Our mission is to advance the art and science of transplant surgery through patient care, research, education, and advocacy.

ASTS supports the efforts of the Department of Health and Human Services (HHS) Office of Civil Rights (OCR) to address issues related to discrimination against the disabled in access to health care services. We applaud the comprehensive approach to this issue reflected in the Proposed Rule, and we believe that finalization of the policies reflected in the Proposed Rule will go a long way toward increasing access to medically necessary health care services for the Nation's disabled population.

#### **ASTS Efforts to Increase Access to Transplantation**

ASTS has long been a strong champion of legislation and policy changes that we believe hold considerable potential to ensure racial/ethnic constructs, disability and socioeconomic status are not barriers to care.

- Over the past decade, ASTS has strongly supported the extension of Medicare coverage of immunosuppressive drugs, and we are gratified that this legislation has been enacted. We believe that the extension of immunosuppressive drug coverage to those without other forms of coverage has the potential to increase both access to transplantation and organ retention for both disabled and non-disabled transplant recipients alike.
- We strongly support legislation that would preclude insurance companies from discriminating against living donors and that would explicitly extend Family Medical Leave Act protections to living donors. In particular, ASTS has been a champion of the Living Donor Protection Act since it was first introduced in Congress, which would address the barriers living donors face when choosing to give the gift of life.
- Through the [National Living Donor Assistance Center \(NLDAC\)](#), ASTS administers the day-to-day operations in support of the HRSA grant "Removing Financial Disincentives to Living Organ Donation."

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- We also strongly support revisions to Transplant Center metrics to remove disincentives to transplantation, which disproportionately impact potential transplant recipients who are considered “high risk.”

In light of these efforts, ASTS is disheartened by the evidence of discrimination against the disabled by some centers that is cited in the preamble to the Proposed Rule. We find it troubling that anyone would be denied a life-saving transplant based purely on any type of disability.

### **Transplantation and the Disabled**

In furtherance of its goal to ensuring the broadest coverage allowable under Section 504, the Proposed Rule updates the definition of “Disability.” With respect to an individual, HHS construes disability to mean “(i) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (ii) a record of such an impairment; or (iii) being regarded as having such an impairment as described in paragraph (f) of this section.”<sup>1</sup> Mirroring current ADA regulations, the Proposed Rule’s definition of disability articulates three methods, or prongs, to determine whether an individual has a disability: 1) the “actual disability” prong, 2) the “record of disability” prong, or 3) the “regarded as being disabled” prong. The Proposed Rule makes it clear that each of these prongs should be interpreted broadly and in favor of expansive coverage.

While current data regarding the proportion of potential transplant recipients who are disabled is not readily available, the data that is available with respect to the kidney transplant target population (those with latter stage Chronic Kidney Disease (CKD) and End Stage Renal Disease (ESRD)) suggests that a significant proportion of potential transplant recipients may be considered to be disabled under the broad definition of “Disability” included in the Proposed Rule.

- Based on 2009 data, the USRDS, as part of its Comprehensive Dialysis Study, reported that only about 25% of ESRD patients <55 years old in the United States reported being able to work for pay and that approximately 80% of the same patients received or had applied for Social Security disability benefits.<sup>2</sup>
- Age-adjusted prevalence of reported limitations on activities of daily living is generally significantly greater for those on disability who have CKD.<sup>3</sup>
- A 2014 analysis conducted by the Centers for Medicare and Medicaid Services suggests that the proportion of the disabled patient population with ESRD reflects significant racial disparities: The percentage of White Medicare beneficiaries with disabilities and ESRD was lower (37.3 percent) than those without ESRD (70.8 percent), while the opposite was true for all other racial/ethnic groups.
- A more recent analysis published in 2000 indicates that while approximately 42 percent of ESRD patients were employed full time before beginning dialysis, only 21 percent were employed when they began dialysis, and only 13 percent were employed a year later.<sup>4</sup> Due to the severe organ shortage, many transplant recipients spend years on dialysis before they are transplanted.

In light of the broad definition of Disability included in the Proposed Rule, ASTS anticipates that a significant proportion of potential transplant recipients will be considered “disabled” for the purposes of Section 504, and ASTS anticipates engaging in a broad educational campaign to ensure that transplant centers are aware of their responsibilities under the regulations once they are issued in final form.

### **ASTS Position on Discrimination Against the Disabled in Transplantation**

ASTS has been in the forefront of efforts to ensure that transplant surgeons and others in the transplant system do not discriminate against disabled transplant candidates. As noted in the preamble to the Proposed Rule, in February 2021, ASTS adopted a [position statement](#) that states:

If the patient has cognitive, physical, or financial limitations that would preclude them from being able to adequately care for themselves, then appropriate social supports or other compensatory mechanisms which would remediate the situation should be identified. If these can be found, then the patient’s candidacy for transplantation should be supported. If, however, they cannot be identified, proceeding with transplantation could threaten both the patient’s health and safety, and the longevity of a donated organ. In such a case, further evaluation should be deferred until the limiting issue can be corrected.

**As such it is the recommendation of the ASTS that no patient will be discriminated against or precluded from transplant listing solely due to the presence of a disability or handicap, whether physical or psychological.** However, if these disabilities lead to a clinical reality where the patient will suffer a great risk of morbidity or mortality from the transplant surgery itself, or the subsequent placement on lifelong immunosuppression, then transplantation would not be recommended. This decision would be made due to the clinical risk benefit analysis for the specific patient, and not on any external factors. (*Emphasis added.*)

In addition, ASTS served a critical role in drafting and supporting AMA's position statement on this issue, [Organ Transplant Equity for Persons with Disabilities D-370.980](#), which states:

1. Our AMA supports: (a) equitable inclusion of people with Intellectual and Developmental Disabilities (IDD) in eligibility for transplant surgery; (b) individuals with IDD who can fulfill transplant center protocols having equal access to organ transplant services and protection from discrimination in rendering these services; and (c) the goal of the Organ Procurement and Transplantation Network (OPTN) in adding disability status to their Nondiscrimination policy under the National Organ Transplant Act of 1984.
2. Our AMA will work with relevant stakeholders to distribute antidiscrimination education materials for healthcare providers related to equitable inclusion of people with IDD in eligibility for transplant surgery.

As these position statements make clear, ASTS strongly believes that discrimination solely on the basis of disability is unjustifiable and that transplant center policies and procedures should be drafted and implemented in a manner that ensures that no potential transplant recipient experiences discrimination solely on the basis of his or her disability. At the same time, we believe that, due to the demands of post-transplant care, all transplant recipients—whether or not they are disabled—should have in place the post-transplant supports necessary to ensure patient and graft survival. We appreciate HHS' recognition that an assessment of the availability of such supports is an integral part of the process of evaluating all potential transplant recipients for inclusion on the transplant waiting list. We also appreciate and support transplant centers' obligations to make reasonable accommodations in assessing this factor in the case of disabled transplant candidates by, for example, considering the availability of family members or social services programs to provide the necessary post-transplant support.

ASTS appreciates the opportunity to comment on the Disability Discrimination Proposed Rule. If you have any questions, please do not hesitate to contact ASTS Associate Director, Advocacy, Emily Besser, MA, CAE at [Emily.Besser@asts.org](mailto:Emily.Besser@asts.org).

Respectfully,



Elizabeth Pomfret, MD, PhD  
President

<sup>1</sup>88 Fed. Reg. at 63,459.

<sup>2</sup>Plantinga LC, Johansen K, Crews DC, Shahinian VB, Robinson BM, Saran R, Burrows NR, Williams DE, Powe NR; CDC CKD Surveillance Team. Association of CKD with disability in the United States. *Am J Kidney Dis.* 2011 Feb;57(2):212-27. doi: 10.1053/j.ajkd.2010.08.016. Epub 2010 Oct 30. PMID: 21036441; PMCID: PMC3025052. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3025052/>.

<sup>3</sup>Id.

<sup>4</sup>ECRI Health Technology Assessment Group. Determinants of Disability in Patients With Chronic Renal Failure: Summary. 2000 May. In: AHRQ Evidence Report Summaries. Rockville (MD): Agency for Healthcare Research and Quality (US); 1998-2005. 13. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK11914/>.