



Chiquita Brooks-LaSure, Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-3409-NC, P.O. Box 8010
Baltimore, MD 21244-8010

February 1, 2022

Submitted electronically via www.regulations.gov.

Re: Docket ID CMS-3409-NC / 86 FR 68594

Dear Administrator Brooks-LaSure:

The National Down Syndrome Society (NDSS) is the leading human rights organization for all individuals with Down syndrome. NDSS envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities. A critical component of creating such a world is ensuring that members of our community have equal access to health care.

We write to respond to the Centers for Medicare & Medicaid Services' (CMS) *Request for Information; Health and Safety Requirements for Transplant Programs, Organ Procurement Organizations, and End-Stage Renal Disease Facilities* at 86 FR 68594 (December 3, 2021). NDSS applauds CMS for highlighting the litany of ways that people with disabilities experience discrimination throughout the organ transplant process and across the ecosystem, and as part of our ongoing efforts to champion inclusive reform throughout the that system, we are grateful for the opportunity to provide recommendations to CMS.

We also wish to acknowledge our colleagues at the National Council on Disability (NCD; the Council), with whom we continue to collaborate on this issue, and as such we wish to echo and excerpt the Council's response to this request for information. Because we agree with how both CMS and NCD have framed the issue of discrimination against people with disabilities in organ transplant discrimination, we limit our response to answering posed questions about equity in organ transplantation:

Responses

Are there revisions that can be made to the transplant program conditions of participation ("CoP") or the organ procurement organization ("OPO") conditions for coverage ("CfC") to reduce disparities in organ transplantation?

Consistent with recommendations from NCD, NDSS recommends that, to reduce disparities regarding individuals with disabilities, CMS revise CoPs and CfCs to incorporate the following actions:

- Include the requirement that transplant programs and OPOs must comply with the nondiscrimination requirements of Section 504 of the Rehabilitation Act of 1973, Section 1557 of the Affordable Care Act, and the Americans with Disabilities Act (ADA).
- Require a disability rights representative on UNOS, OPTN, and Medicare and Medicaid boards and key committees to help ensure that waitlists are utilized in a non-discriminatory manner, and to reform any guidelines that could be interpreted by organ transplant programs as allowing people with disabilities to be kept off the waitlist for a transplant.
- Require that organ procurement data collection incorporate disability information pertaining to the organ donor, including primary diagnosis and type of disability.

What changes can be made to the current requirements to ensure that transplant programs ensure equal access to transplants for individuals with disabilities?

Consistent with recommendations from NCD, NDSS recommends that CMS revise current requirements to incorporate the following actions:

- Clarify transplant programs' obligations under Section 504, Section 1557, and the ADA, including the obligation for individualized assessments and reasonable modifications, including and especially considering not only the person's ability to manage post-operative care independently, but the full range of supports and services available to help the individual manage post-operative care, such as family members, programs, and service providers; and the provision of necessary auxiliary aids and effective communication needed for a successful organ transplant and postoperative regimen.
- In the case of individuals who, but for their disability, would receive referrals of for an organ transplant, admission to an organ transplant program, or placement on a waiting list for an organ transplant, require these services be rendered.
- Prohibit transplant program policies or practices that treat intellectual and developmental disabilities as an absolute contraindication to a transplant.
- Develop and promote best practices and technical assistance for health care providers to understand how to incorporate disability appropriately into treatment plans, such as through consideration of co-occurring medical conditions, without considering disability a dispositive contraindicator to organ transplant.
- Require transplant centers to provide supported decision-making when needed to assist people with disabilities undergoing the organ transplantation process.
- Develop technical assistance, in collaboration with the HHS Office for Civil Rights, educational institutions, and disability community advocates, to help health care providers throughout the organ transplant ecosystem understand legal requirements as well as inclusive and disability justice-based practice.

- Ensure that all materials are available in accessible and user-friendly formats, inclusive of different communication needs.
- Ensure that practitioners throughout the ecosystem are prepared, including through training, to make reasonable modifications to policies, practices, and related services.
- Ensure that timely review is a key component in any dispute resolution processes related to patient care in organ transplantation.

What changes can be made to the current requirements to address implicit or explicit discrimination, such as decisions made based on faulty assumptions about quality of life and the ability to perform post-operative care?

Systemic change requires systemic advocacy. NDSS believes that preventing discrimination against people with disabilities in the organ transplant ecosystem requires partnership between governmental entities, community-supporting organizations, and the disability community itself. As we have continued to promote anti-discrimination in this area, the primary problem we have encountered is not outright bigotry, but rather a widespread lack of awareness that this discrimination exists. While there will always be those who believe that the life of a person with Down syndrome or other disability inherently has less value than the life of a nondisabled person, we are working each day to break down this ignorant and outdated notion. Education of all participants who have touchpoints with the organ transplant process, whether on the patient- or provider-side, is critical. With support from CMS and other parts of the government, our organizational partners, and our community, NDSS believes that great strides are being made to ensure that individuals with Down syndrome and other disabilities receive the same access to quality health care as those without disabilities.

We thank the Centers for Medicare & Medicaid Services for the opportunity to provide comments on this request for information. The National Down Syndrome Society is eager to work with CMS to promote positive outcomes for the Down syndrome community throughout the organ transplant ecosystem. For further information regarding these comments, please contact us at info@ndss.org.

Sincerely,



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National Down Syndrome Society