

July 10, 2018

Roger Severino  
Director  
Office for Civil Rights  
U.S. Department of Health and Human Services  
200 Independence Avenue, SW  
Hubert Humphrey Building  
Washington, D.C. 20201

Lance Robertson  
Administrator and Assistant Secretary for Aging  
Administration on Community Living  
U.S. Department of Health and Human Services  
200 Independence Avenue, SW  
Hubert Humphrey Building  
Washington, D.C. 20201

RE: Withholding of Life-Sustaining Treatment

Dear Director Severino and Administrator Robertson:

On behalf of a broad coalition of groups committed to the equality and dignity of people with disabilities, we write to urge you to address the critical issue of the withholding of life-sustaining treatment from people with disabilities.

For some time now, disability rights advocates have been concerned by formal and informal clinical practices that discriminate against people with disabilities in accessing life-saving medical treatment. These range from refusing to provide people with disabilities with access to scarce medical resources to the denial or withdrawal of life-sustaining care without the individual's or the family's consent, due to the medical professional's value judgements or perceptions regarding a disabled person's quality of life.

The FY 2018 House Appropriations Committee report for HHS Office of Civil Rights notes that "the Committee is concerned about reports of continued discrimination against persons with disabilities in organ transplant." Disability advocates have long requested that HHS OCR issue additional guidance clarifying transplant center responsibilities under the Americans with Disabilities Act and Section 504 of the Rehabilitation Act.

We support these requests and urge you to work with the disability community to craft guidance to protect the rights of people with disabilities to access organ transplantation. We believe such guidance must fully enforce both the non-discrimination and the reasonable accommodation requirements of federal disability laws, particularly as they relate to considering whether an individual with a disability is able to manage post-operative care requirements. We applaud OCR's commitment to "ensuring non-discrimination in organ transplant decision-making"

reflected in its FY 2019 Justification of Estimates for Appropriations Committees and look forward to concrete accomplishments in this area.

We are also concerned about the potential for disability discrimination in the application of futile care policies, which articulate how hospitals and other health care institutions will address conflicts between physicians and patients (or their families) regarding the continuation of treatment that a clinician deems to be “futile care.” While we recognize that futility policies may play an important role in medical care in some cases, we are concerned that medical determinations of futility are at times motivated by inappropriate considerations of cost or value judgments regarding the quality of life of people with disabilities seeking life-saving medical treatment, rather than an objective assessment of the individual’s ability to benefit from treatment. We urge HHS to work with the disability community to issue guidance on this topic, using the statutory authorities available to it under the Americans with Disabilities Act and Section 504 of the Rehabilitation Act.

People with disabilities deserve an equal opportunity to access lifesaving health care, including when that care necessitates the use of scarce healthcare resources, such as organ transplants. Similarly, it is important to recall that individuals with disabilities and their families may possess different perceptions of their quality of life than those held by clinicians or non-disabled people unfamiliar with the lived experience of disability, particularly when appropriate services and supports are provided in a manner consistent with federal law.

We believe that the cause of human dignity is intrinsically connected to the broader mission of disability rights, equality and inclusion. Equitable treatment in health care settings must be part of our society’s evolution in how it treats people with disabilities. Existing law provides your offices the ability to take meaningful action to address these issues. It is our hope that we can work collaboratively with you on how best to address these issues in a comprehensive fashion.

Please do not hesitate to contact Vania Leveille, senior legislative counsel, at [vleveille@aclu.org](mailto:vleveille@aclu.org) if you have any questions or need additional information.

Sincerely,

American Civil Liberties Union  
American Association on Intellectual and Developmental Disabilities  
American Association of People with Disabilities  
American Physical Therapy Association  
Autistic Self Advocacy Network  
The Arc of the United States  
ACCSES  
Association of University Centers on Disability  
Bazelon Center for Mental Health Law  
Center for Public Representation  
Council on Quality and Leadership  
Disability Rights Education and Defense Fund

Lutheran Services in America-Disability Network  
National Association of Councils on Developmental Disabilities  
National Council on Independent Living  
National Down Syndrome Congress  
National Down Syndrome Society  
National Disability Rights Network  
National Organization of Nurses with Disabilities  
National Health Law Program  
Not Dead Yet  
TASH