

March 20, 2020

The Honorable Alex Azar Secretary U.S. Department of Health and Human Services 200 Independence Avenue S.W. Washington, D.C. 20201

Roger Severino
Director
Office of Civil Rights
U.S. Department of Health and Human Services
200 Independence Avenue S.W.
Washington, D.C. 20201

Dear Secretary Azar and Director Severino:

We write as co-chairs of the Consortium for Citizens with Disabilities (CCD) Rights and Health Task Forces to urge you to ensure that, if the current pandemic results in government decisions to ration treatment, decisions about how medical treatment should be allocated are made without discriminating based on disability. The CCD is the largest coalition of national organizations working together to advocate for Federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

News sources have widely reported on the use of treatment rationing decisions in Italy as the coronavirus pandemic overwhelms the medical system's capacity, including supplies, staff, and intensive care hospital capacity. Those decisions have relied on principles disadvantaging people with disabilities and older adults. We are extremely concerned about the potential impact on people with disabilities and older adults if government or private entities in the United States were to employ rationing decisions based on similar principles. Indeed, proposed schemes for rationing of treatment in the United States have already begun to surface. See, e.g., Ezekiel J. Emanuel, James Phillips, and Govind Persad, "Opinion | How the Coronavirus May Force Doctors to Decide Who Can Live and Who Dies," *The New York Times*, March 12, 2020, https://www.nytimes.com/2020/03/12/opinion/coronavirus-hospital-shortage.html.

Your office has long stood on guard against medical rationing schemes that discriminate against and otherwise devalue the lives of people with disabilities. In 1992, then-Secretary Louis Sullivan,

relying on advice from your office and the Department of Justice, rejected Oregon's proposed health plan precisely because its rationing provisions discriminated in violation of the Americans with Disabilities Act. In support of that decision, Secretary Sullivan explained that a covered entity may consider "a wide range of factors" that are "consistent with the ADA." Covered entities, he explained, "may consider, consistent with the ADA, any content neutral factor that does not take disability into account or that does not have a particular exclusionary effect on persons with disabilities." But they may not discriminate against qualified individuals with disabilities. Nor may they employ factors that rest "in substantial part on the premise that the value of the life of a person with a disability is less than the value of the life of a person without a disability."

It is now urgent that this office reaffirm that longstanding position. We believe it is critical for HHS to clearly convey—and to ensure—that any protocols that may be implemented for rationing treatment comply with the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973. As you know, Title II of the ADA bars disability-based discrimination in programs, services and activities of state and local government entities. Title III bars such discrimination in public accommodations, including private medical providers. Section 504 of the Rehabilitation Act bars disability-based discrimination in programs and activities of federal executive branch agencies and certain recipients of federal financial assistance. While we recognize that very difficult choices concerning the allocation of treatment may be necessary as the pandemic proceeds, those decisions must be made consistent with federal law. The lives of people with disabilities are equally valuable to those without disabilities, and healthcare decisions based on devaluing the lives of people with disabilities are discriminatory.

First and foremost, the ADA and Section 504 require that government decisions about how treatment should be allocated must be made based on individualized determinations, using current objective medical evidence, and not based on generalized assumptions about a person's disability. The mere fact that a person has diabetes, depression, an intellectual disability, or a mobility impairment, for example, cannot be a basis for denying care or making that person a lower priority to receive treatment.

Second, the ADA and Section 504 prohibit treatment allocation decisions from being made based on misguided assumptions that people with disabilities experience a lower quality of life, or that their lives are not worth living. Such inaccurate assumptions continue to be pervasive in our society, and there is a widespread lack of understanding about how people with significant disabilities can live fully, enjoy their lives as much as anyone else, achieve as much or more than others, and where necessary develop alternative strategies to accomplish goals that others assume are off-limits to them.

Third, the ADA and Section 504 prohibit treatment allocation decisions from being made based on the perception that a person with a disability has a lower prospect of survival. While the possibility of a person's survival may receive some consideration in allocation decisions, that consideration must be based on the prospect of surviving the condition for which the treatment is designed—in this case, COVID-19—and not other disabilities. In addition, it must be based on a

¹ Analysis Under the Americans with Disabilities Act (ADA) of the Oregon Reform Demonstration (Attachment to Letter from Louis W. Sullivan to Governor Barbara Roberts (Aug. 3, 1992)), reprinted in 9 *Issues in Law & Medicine* 397 (1994).

 $^{^{2}}$ Id.

³ *Id*.

clear indication from the person's individual circumstances that the person is unlikely to survive or to benefit from treatment.

Fourth, the ADA and Section 504 prohibit treatment allocation decisions from being made based on the perception that a person's disability will require the use of greater treatment resources. Reasonable modifications must be made where needed by a person with a disability to have equal opportunity to benefit from the treatment. These may include interpreter services or other modifications or additional services needed due to a disability.

Fifth, a person with COVID-19 is "qualified" for purposes of receiving COVID-19 treatment if he or she can benefit from the treatment (that is, can recover) and the treatment is not contraindicated.

The Age Discrimination Act prohibits similar forms of discrimination based on age.

In all of these instances, this Office must ensure that decisions regarding the possibility of benefit, the prospect of survival, and the use of treatment resources are free from bias or stereotype. The bias against individuals with disabilities and older adults by medical professionals has been well documented, and it often expresses itself in exaggerated fears about the cost, burden, or futility of treatment of such individuals. This Office has long stood on guard against those biases, and it should do so again.

We urge you to act swiftly to convey this information to all entities who may be involved in such decision-making, and to make clear that HHS will enforce federal laws including the ADA and Section 504.

Sincerely,

Jennifer Mathis

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