



National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families

March 18, 2020

Roger Severino
Director, Office for Civil Rights
U.S. Department of Health & Human Services
200 Independence Avenue, S.W.
Washington DC 20201

Dear Mr. Severino:

On behalf of the National Council on Disability (NCD), I write on a matter of urgency regarding non-discriminatory access to life-saving medical care for people with disabilities who contract COVID-19. Due to the concerns detailed in this letter regarding the predicted impact of COVID-19 on people with existing medical conditions coupled with predicted rationing of life-saving care, NCD requests that the Office for Civil Rights (OCR) quickly issue a notice to physicians and hospitals specifying the applicability of non-discrimination requirements of the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act in making treatment decisions. When OCR talks, the medical community listens, and OCR has a window of opportunity now, before physicians become overwhelmed with COVID-19 patients, to provide necessary information to the medical community about the provision of non-discriminatory care.

Current projections show that the need for intensive medical care for victims of COVID-19 will far exceed the resources of the US healthcare system, and medical professionals are already predicting the certainty that emergency and intensive care will have to be rationed. The lack of resources to treat the population who will contract COVID-19 creates a deadly outlook for people with disabilities. This is not hyperbole – the people most susceptible to COVID-19 have medical conditions, e.g., weakened immune systems, heart disease, diabetes – exactly the people who will be most impacted by emergency or intensive care rationing. Physicians will have to make decisions on who will get life-saving care, and who will not.

Unfortunately, as OCR knows, people with chronic illnesses and other disabilities have been left behind, denied resources to survive, and as a result, have suffered great losses of life because of lack of emergency preparation that respects every life, and by outright discrimination by medical practitioners who, through ignorance of the law or due

to the belief that people with disabilities are less valuable, and therefore less deserving of medical care, than those who are not. Such prejudice has fed into the belief that people with disabilities, especially the most weak and vulnerable, should be put out of their misery. NCD opposes these views and any medical actions that implicitly and explicitly disregard the dignity of the lives of people with disabilities. These beliefs have always been dangerous – but COVID-19 raises NCD's concerns to an unprecedented level.

OCR is aware of the historic and persistent discrimination against people with disabilities in healthcare. We documented this issue in our recent reports on bioethics and disability, explaining that the lives of persons with disabilities continue to be devalued in the medical profession due to pervasive negative biases and inaccurate assumptions. The belief that people with disabilities have a lesser quality of life and are less valuable to society, has led to deadly consequences - physicians choosing to provide medically scarce resources to non-disabled or healthier people – a violation of human rights, civil rights and a reinforcement of the belief that people with disabilities are lesser-than and less deserving of life itself.¹ Indeed, recent articles regarding the likely response to COVID-19 published by major media outlets are already predicting – unapologetically - that the lack of capacity of the US healthcare system is going to result in rationing of life-saving care for people with chronic illnesses and pre-existing disabilities.² Such discourse has deep historical foundations that has led to discrimination and access to healthcare, including life-saving care, for people disabilities throughout the nation's history. Once again, society, including physicians, is already accepting the conclusion that this group will be denied the right to life due to a lack of resources. Once again, it is a forgone conclusion that people with disabilities are the most expendable group. Once again, as in previous natural disasters and medical crises, people with disabilities are being told to prepare to die.

OCR has recognized the long-standing discrimination against people with disabilities, taking action to address discrimination on a case by case basis, but the world has changed - we are experiencing a quickly progressing medical crisis which will disproportionately impact people with disabilities on a broad scale. OCR should rapidly head off what could be yet another time in US history when people with disabilities are left to die because medical decisions remain infused with disability bias or because physicians are not aware of their responsibilities under the Americans with Disabilities Act, the Rehabilitation Act, and the Affordable Care Act. More evidence of the need for immediate OCR action is found in a cursory review of State protocols for standards of medical care for times of crisis – like a pandemic - that show that people with existing

¹ <https://ncd.gov/publications/2019/bioethics-report-series>

² <https://www.washingtonpost.com/health/2020/03/15/coronavirus-rationing-us/>; <https://www.nytimes.com/2020/03/12/opinion/coronavirus-hospital-shortage.html>; <https://www.washingtonpost.com/opinions/2020/03/15/nightmare-rationing-health-care/>

disabilities will be, if the plans remain the same, discriminated against in the provision of COVID-19 care.³

Because this historic pandemic disproportionately threatens the lives of people with disabilities, NCD strongly urges OCR to immediately issue a notice to the nation's medical providers of their obligations for non-discriminatory medical care under the ADA, the Rehabilitation Act, and the Affordable Care Act. The notice should include a statement on the historic and deep-seated biases and stereotypes about people with disabilities that have resulted in eugenics and lack of life-saving care, ask physicians to be mindful of this when making medical treatment decisions, and make clear that, even in an environment where health care resources are limited, the civil rights of people with disabilities cannot be suspended or limited.

Thank you for your work to ensure access to medical care for all people and your efforts to address disability discrimination in health care. OCR's efforts have improved the lives of people with disabilities and your leadership is valued and appreciated.

If you wish to discuss this with me directly I would be delighted to do that at your convenience. However, if a member of your team would like to discuss this with a member of my team please have them contact Lisa Grubb, Executive Director and CEO at lgrubb@ncd.gov, Joan Durocher, General Counsel and Director of Policy at jdurocher@ncd.gov, and Ana Torres-Davis, Senior Attorney-Advisor at attoresdavis@ncd.gov.

Respectfully,



Neil Romano
Chairman

³ AL: <http://www.adph.org/CEP/assets/VENTTRIAGE.pdf>;
AZ: <https://www.azdhs.gov/documents/preparedness/emergency-preparedness/response-plans/azcsc-plan.pdf>; CO: <https://cha.com/wp-content/uploads/2018/10/Crisis-Standards-of-Care-05102018-FINAL.pdf>; FL: <http://www.floridahealth.gov/programs-and-services/emergency-preparedness-and-response/healthcare-system-preparedness/documents/acs-guide.pdf>;
MN: <https://www.health.state.mn.us/communities/ep/surge/crisis/standards.pdf>
NY: https://www.health.ny.gov/regulations/task_force/reports_publications/docs/ventilator_guidelines.pdf
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TN: [https://www.tn.gov/content/dam/tn/health/documents/2016 Guidance for the Ethical Allocation of Scarce Resources.pdf](https://www.tn.gov/content/dam/tn/health/documents/2016_Guidance_for_the_Ethical_Allocation_of_Scarce_Resources.pdf)
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