



March 30, 2020
By Electronic Mail

Governor John Bel Edwards
Secretary Stephen Russo
Lt. Gov. Billy Nungesser
Attorney General Jeffrey Landry
Senate President Patrick Cortez
Speaker of the House Clay Schexnayder

Dear Governor Edwards and other distinguished State officials:

We write on an urgent matter regarding non-discriminatory access to life-saving medical care for people with disabilities, including those with psychiatric, developmental, intellectual and physical conditions who contract COVID-19. While the impacts of the current COVID-19 crisis are felt throughout Louisiana in a myriad of ways, there is no greater concern than access to life saving care, and the ability of our health care system to respond to the anticipated need for intensive care and ventilator access for thousands of residents.

People with disabilities are, and will be, at high risk of contracting COVID-19. Those risks are especially severe for people in congregate residential programs, state-operated institutional settings, prisons and jails, and long-term care facilities. We recognize and appreciate that Louisiana is already making efforts to protect these residents' safety and their access to medically necessary services.

At this moment, we ask that state officials take specific steps that are critical to ensure that life-saving care is not illegally withheld from citizens with disabilities, including aging adults with co-morbid conditions, due to discriminatory resource allocation or diminished standards of care.

All state and private entities overseeing the delivery of life-saving medical interventions must make treatment decisions consistent with the non-discrimination requirements of the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act. Yet around the country national and state advocacy groups are

confronting outdated and discriminatory policies on emergency resource allocation in which individuals with specific disabilities or functional impairments can be denied access to, or subjected to the removal of, medically necessary ventilators.¹

Disability Rights Washington and several organizations joined to file a complaint against the state of Washington with the Office for Civil Rights for the U.S. Department of Health and Human Services for guidance on who receives a bed in the intensive care.² That guidance discriminates against people with disability by authorizing the denial of treatment or lowering the priority of people with disabilities based on negative stereotypes about the quality of life, overall health and the intrinsic value of people with disabilities. Washington’s guidance is currently displayed on the Louisiana Department of Health’s website for COVID-19 under the heading of “Scarce Resource Management & Crisis Standards of Care.”³ This guidance encourages discrimination and endangers the lives of people with disabilities. We call on LDH and the Governor’s office to remove it immediately and replace it with guidance that respects the lives and worth of people with disabilities.

In response to such policies, the National Council on Disability (NCD)⁴ and the Consortium for Citizens with Disabilities (CCD)⁵ have proposed important principles for the delivery of care. In keeping with those national organizations, and consistent with our respective organizations’ missions, we urge Louisiana to immediately adopt and disseminate mandatory statewide guidelines which clarify the following:

- 1) that the ADA and Section 504 require government decisions regarding the allocation of treatment/life-saving resources to be made based on individualized determinations, using current objective medical evidence, not generalized assumptions about a person’s disability;
- 2) that the ADA and Section 504 prohibit treatment allocation decisions based on misguided assumptions that people with disabilities experience a lower quality of life, or that their lives are not worth living;

¹ Office of Civil Rights complaints filed against the States of Washington and Alabama can be found at <https://www.centerforpublicrep.org/news/cpr-and-partners-file-second-complaint-regarding-illegal-disability-discrimination-in-treatment-rationing-during-covid-19-pandemic/>

² Whose Life is Worth Saving? In Washington State, People With Disabilities Are Afraid They Won’t Make the Cut, Mike Baker, New York Times, March 23, 2020, available at <https://www.nytimes.com/2020/03/23/us/coronavirus-washington-triage-disabled-handicapped.html>

³ <http://ldh.la.gov/index.cfm/page/3880> and http://ldh.la.gov/assets/oph/Coronavirus/resources/providers/Scarce_Resource_Management_and_Crisis_Standards_of_Care_Overview_and_Materials2020-3-16.pdf

⁴ See, Letter of National Council to Roger Severino, Director, Office for Civil Rights, U.S. Department of Health & Human Services, March 18, 2020, available at <https://ncd.gov/publications/2020/ncd-covid-19-letter-hhs-ocr>

⁵ 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.

- 3) that the ADA and Section 504 prohibit treatment allocation decisions based on the perception that a person with a disability has a lower prospect of survival;
- 4) that the ADA and Section 504 prohibit treatment allocation decisions based on the perception that a person's disability will require the use of greater treatment resources; and
- 5) that a person 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.⁶

Louisiana's current policies do not directly address the resolution of critical questions concerning how allocation of resources will occur at a time when demand exceeds system capacity. Nor do they provide specific guidance to private hospitals and ethics committees who will be on the front lines of thousands of individual treatment decisions. Louisiana may be in the position of having to make rationing decisions on the use of ventilators in a matter of days.⁷ Without guidance from state authorities, allocations may be made based on discriminatory criteria, including utilitarian and even eugenicist assessments of the value of the patient's life.⁸

In a medical setting, the lives of people with disabilities are often at the greatest risk. Even changes to the standard of care for all patients, such as implementing a "universal do not resuscitate" order,⁹ would disproportionately prevent people with disabilities from receiving life-saving care. It is important that Louisiana act quickly to ensure that rationing criteria and standards of care reflect evidence-based medical science and the intrinsic value of all human life.

Louisiana needs a set of mandatory principles like those listed above, prohibiting discrimination and requiring the application of individualized and objective medical standards

⁶ See, Consortium of Citizens with Disabilities, letter to Secretaries of EOHHS and the Office of Civil Rights, March 20, 2020, available at <http://www.c-c-d.org/fichiers/Letter-re-COVID-19-and-Disability-Discrimination-final.pdf>

⁷ New Orleans on Track to Run Out of Health Care Capacity by 1st Week of April, John Bel Edwards Says, Sam Karlin, The Advocate, March 24, 2020; Even with Coronavirus Disaster Declaration, Louisiana's Ventilator Capacity is 'Far from OK', Sam Karlin, The Advocate, March 24, 2020.

⁸ May Hospitals Withhold Ventilators from COVID-19 Patients with Pre-Existing Disabilities? Notes on the Law and Ethics of Disability-Based Medical Rationing, Samuel R. Bagenstos, University of Michigan Law School, pp. 8-10, March 24, 2020, available at https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3559926. An article published this week in the New England Journal of Medicine applies this rationale even to removing the existing use of a ventilator from one person, to provide it to another, with the aim of "maximizing benefits." <https://www.nejm.org/doi/full/10.1056/NEJMs2005114?query=RP> This reasoning could be used to justify the repossession of ventilators currently being used by persons with disabilities for conditions that began long before COVID-19, for example ALS patients, and evokes long-repudiated theories of eugenics.

⁹ Hospitals Consider Universal Do-Not-Resuscitate Orders for Coronavirus Patients, Ariana Eunjung Cha, Washington Post, March 25, 2020 available at <https://www.washingtonpost.com/health/2020/03/25/coronavirus-patients-do-not-resuscitate/>

that deny or remove care only when continued treatment would be futile. Without the creation of a statewide policy, and a meaningful appeal process, the exercise of medical discretion across Louisiana will be largely unchecked, unguided, and subject to wide variation. The unavoidable result will be highly subjective decision-making, needlessly placing even greater stress on treating professionals.

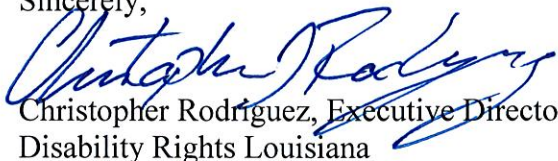
Failure to act also presents the unacceptable risk that misplaced societal views about the relative quality or value of the lives of people with disabilities will result in their denial of life-saving treatment.

We are on the precipice of a statewide crisis in access to care, as the Governor has made clear in recent press briefings. We applaud the strategic steps being taken to avert a crisis in managing both the rates of COVID-19 infection and the comprehensiveness of Louisiana's response. Louisiana has an opportunity to be a national leader on these issues, by acting to establish equitable and nondiscriminatory standards of care before scarcity begins driving medical decisions across Louisiana.

We stand ready to assist in these efforts, and can quickly bring to bear a range of local and national resources and expertise, including emerging best practices, to support the Governor, the COVID-19 command center, and the Department of Health. At a minimum, we ask that you confirm your receipt of this letter and make clear how Louisiana intends to address the disability community's concerns regarding discriminatory rationing of care.

Thank you in advance for your consideration of this most important issue, and for your long-standing commitment to all Louisiana's citizens with disabilities. If you have any questions or would like to discuss this further, you may reach me at: crodriguez@disabilityrightsla.org.

Sincerely,


Christopher Rodriguez, Executive Director
Disability Rights Louisiana

Supported by:

Louisiana Center for Children's Rights
Southern Poverty Law Center
Louisiana Developmental Disabilities Council
Families Helping Families (FHF) - North East Louisiana
Families Helping Families (FHF) - Greater New Orleans
Families Helping Families (FHF) - Baton Rouge
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