



DISABILITIES LAW PROGRAM

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By Email

Governor John Carney
Secretary Dr. Karen Odom Walker, Department of Health and Social Services
Dr. Karyl Rattay, Director, Division of Public Health
Dr. Richard Hong, Medical Director, DPH Office of Preparedness

Dear Governor Carney, and Doctors Walker, Rattay, and Hong:

I write on a matter of urgency regarding non-discriminatory access to life-saving medical care for people with disabilities across the lifespan, including those with psychiatric, developmental, intellectual and physical conditions who contract COVID-19. I am the Project Director of the Disabilities Law Program (DLP) of Community Legal Aid Society. The DLP is the federally mandated protection and advocacy system for individuals with disabilities in Delaware.

While the impacts of the current COVID-19 crisis are felt throughout Delaware 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 hundreds if not thousands of residents. People with disabilities are, and will be, at high risk of contracting COVID-19, particularly those who are in congregate residential programs, state-operated institutional settings, prisons and jails, and long term care facilities. We recognize and appreciate that Delaware is already making tremendous efforts to protect these residents' safety and their ability to access medically necessary services.

At this moment, it is also critical that state officials take specific steps to ensure that life-saving care is not illegally withheld from Delawareans with disabilities, including aging adults with co-morbid conditions, due to discriminatory resource allocations or altered standards of care. Such access to care includes access to ventilators and other critical care interventions, and access to Personal Protective Equipment (PPE) for individuals and their caregivers who are not hospitalized but remain vulnerable in their own homes, group homes and other supported living arrangements.

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 emergency resource allocation policies; these policies permit healthcare providers to restrict or remove medically necessary ventilators from individuals with specific disabilities or functional impairments.¹ The United States Department of Health and Human Services Office of Civil Rights issued guidance in the last few days making clear that the laws and principles of non-discrimination apply to policies and decisions related to access to medical care.² The Guidance emphasizes the need for clearly defined, nondiscriminatory procedures for dealing with the potential and anticipated shortages of critical medical supplies amid the Covid-19 pandemic.

It is my understanding that the State of Delaware's Public Health Medical Ethics Advisory Committee to the Office of Preparedness has been reviewing and revising the Crisis Standards of Care for some time, and that some of the more discriminatory provisions of earlier policies have been removed or otherwise addressed. Hopefully, the principles listed below have already been incorporated in the document. We may have more concrete suggestions or concerns after reviewing the policy and request a copy of the latest draft for that purpose.

The National Council on Disability (NCD)³ and the Consortium for Citizens with Disabilities (CCD)⁴ have proposed important principles for the delivery of care. In keeping with those national organizations, and consistent with my agency's core values as the protection and advocacy system in Delaware, we urge Delaware 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;
- 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;

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/>. OCR complaints have also been filed against Kansas and Tennessee.

² Office of Civil Rights Bulletin, 3/28/2020; <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>

³ 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>

⁴ 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.

- 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.⁵

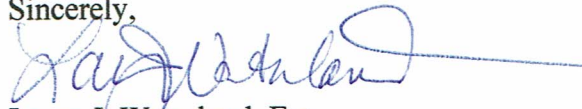
We urge the creation of statewide guidance and also communication and oversight to ensure that facilities and providers statewide understand and commit to following that guidance. Without the creation of a statewide policy, and a meaningful appeal or review process, the exercise of medical discretion across Delaware will be largely unchecked, unguided, and subject to wide variation. The unavoidable result will be highly subjective decision-making, needlessly placing even greater responsibility and stress on treating professionals.⁶ 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 applaud the strategic steps being taken to avert a crisis in managing both the rates of COVID-19 infection and the comprehensiveness of Delaware's response. Delaware has an opportunity to be a national leader on these issues, by acting to establish equitable, democratic and nondiscriminatory standards of care before scarcity begins driving medical decisions across the state.

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 Department of Health and Social Services and the Division of Public Health. At a minimum, we ask that you confirm your receipt of this letter, assuring us that Delaware intends to continue to address the disability community's concerns regarding discriminatory rationing of care, and that you share a copy of the Crisis Standards of Care with us as soon as possible. Transparency regarding this highly sensitive and critical issue is imperative.

Thank you in advance for your consideration of this most important issue, and for your long-standing commitment to Delawareans with disabilities.

Sincerely,



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⁵ 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>

There is also concern regarding "universal DNR orders for patients with COVID-19. See <https://www.washingtonpost.com/health/2020/03/25/coronavirus-patients-do-not-resuscitate/>. The DLP is concerned about any policy that does not include an individualized assessment of risk/ benefit for a medical intervention.