March 20, 2020

The Honorable Gavin Newsom
California State Capitol
1303 10th Street, Suite 1173
Sacramento, California 95814

Re: Survival of People with Disabilities During COVID-19 Pandemic

Dear Governor Newsom:

People with disabilities and chronic health conditions are doubly vulnerable during the COVID-19 crisis: they are vulnerable to acquiring the virus and to suffering more severe effects, and they are vulnerable to healthcare discrimination that may deny them necessary care. As a result, Californians with disabilities and chronic health conditions are experiencing escalating fear and anxiety, on top of any physical effects of viral illness. We need your continued leadership to communicate and ensure that California will protect the rights and access to care of disabled people of all ages.

The Disability Rights Education and Defense Fund is a national cross-disability law and policy center that protects and advances the civil and human rights of people with disabilities through legal advocacy, training, education, and development of legislation and public policy. We are committed to increasing accessible and equally effective healthcare for people with disabilities and eliminating persistent health disparities that affect the length and quality of their lives. DREDF’s work is based on the knowledge that people with disabilities of varying racial and ethnic backgrounds, ages, genders, and sexual orientations are fully capable of achieving self-sufficiency and contributing to their communities with access to needed services and supports and the reasonable accommodations and modifications enshrined in U.S. law.

DREDF thanks you for the swift and decisive actions that you have taken to protect the people of California from COVID-19. Your decision to invoke a state-wide “shelter in place” order will protect people with disabilities and their families from the virus’s accelerating community spread. We now ask that you take the following actions to ensure that people with disabilities receive equitable and effective healthcare in California, which will, in turn, help maintain the health of all Californians.
Prevent and Prohibit Medical “Rationing” Based on Disability

The prospect of shortages of medical staff and equipment for treating those made severely ill by COVID-19 has triggered discussion of “rationing” medical care.

While the coronavirus crisis poses serious challenges to our social and health care systems, state and federal laws including the ADA, Section 504, Section 1557 of the ACA, the Unruh Civil Rights Act, and Gov. Code § 11135 prohibit any “rationing” measures by public or private entities which discriminate on the basis of disability. Denying care to disabled individuals who are likely to benefit from care is unlawful.

Moreover, swift and efficient action now may prevent or ameliorate the need for rationing. In 2008, the California Department of Public Health reported that it had 50.9 million N-95 respirators and 2,400 ventilators to help healthcare providers respond to an emergency in California.¹ There are additional reserves of ventilators and other medical equipment and supplies maintained by hospitals and the U.S. Department of Defense and the Centers for Disease Control and Prevention.² California must follow its own policy statements to ensure that these stockpiles are allocated based on objective need – and distributed throughout the state of California so that health care workers have them on site.³ If existing numbers are projected to be insufficient, California must procure additional equipment and supplies. The

---


³ Surge Standards, Foundational Knowledge, § 8.4.3, Allocation of Ventilators for Pandemic Influenza, [http://www.cidrap.umn.edu/sites/default/files/public/php/258/258_foundation.pdf](http://www.cidrap.umn.edu/sites/default/files/public/php/258/258_foundation.pdf) (“[T]he allocation of ventilators from State and federal stockpiles must take into account the ratio of local populations to available resources, designating appropriate resources for the most vulnerable who are most likely to suffer the greatest impact in any disaster.”).
Governor should speak out about these efforts to alleviate widespread fear and anxiety among vulnerable populations, including Californians with disabilities.

We further urge the Governor and state agencies to swiftly issue a directive to health plans and insurers, hospitals, and other medical providers on maintaining their obligations under state and federal disability nondiscrimination laws during the coronavirus crisis, including in the allocation of scarce medical resources. Such guidance should include the following basic principles:

- The presence of a disability, including a significant disability, is not a permissible basis for denying people access to care or giving them a lower priority for care.

- The fact that a disabled person may have a lower likelihood of survival is not a permissible basis for denying care or allocating the person a lower priority for care. If the person will benefit from care, then they are entitled to access care on an equal basis as others.

- The fact that a person with a disability may require reasonable accommodations during treatment, or more intensive treatment, is not a permissible basis for denying care or allocating the person a lower priority for care.

- All medical decisions about providing care must be based on current objective medical evidence, and not based on generalized assumptions about a person’s disability. Treatment decision may not be made based on misguided assumptions that people with disabilities experience a lower quality of life.

Covered entities should be permitted to prioritize those with a greater urgency of need, and delay non-urgent care. They need not allocate scarce resources to individuals with no chance of survival. But people with disabilities should not face discrimination in seeking life-sustaining care that they will benefit from.\(^4\) 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.

\(^4\) Sample protocols on the allocation of ventilators violate these principles where they permit denial of care to disabled people who will benefit from it. See id. California should disavow such denials as contrary to law and public policy.
Ensure Access to Home-and Community-Based Services and Related Services

Individuals with various disabilities who rely on personal care assistance face a dilemma during the COVID-19 crisis. No person with a disability should have to choose between catching a potentially deadly new virus and receiving the assistance needed to perform critical activities of daily living such as toileting, eating, dressing, and managing medications. No personal care assistant, whether paid or unpaid, should be required to perform their duties without proper protective equipment to ensure both their own well-being as well as the continued well-being of their own families and other clients with disabilities, or face the ethical dilemma of rendering necessary duties while beginning to feel sick. The following measures are needed to preserve the well-being of people with disabilities while they shelter in place:

- Fund and establish backup personal care assistant (PCA) registries, for both public and private pay PCAs, and establish streamlined on-call emergency back-up alternatives to ensure PCA services when scheduled PCAs are unavailable.

- Place a moratorium on In-Home Supportive Services (IHSS) reassessments that could lead to service hour reductions, and suspend policies that deny overtime to IHSS workers.

- Provide and efficiently distribute protective gear for paid and unpaid PCAs, including family, friends, and volunteers who are providing personal attendant services.

- Include disability-specific providers and needs within guidance on categories of “essential business” and “essential personnel,” such as public and private personal care attendants, public transit and paratransit, privately contracted Non-Emergency Medical Transportation (NEMT) providers, durable medical equipment providers/repairers, and veterinarians.

Even short gaps in coverage of personal care attendants and related services can lead to worsened health and unnecessary institutionalization, contrary to the integration principles adopted by the U.S. Supreme Court in *Olmstead v. L.C.*, 527 U.S. 581 (1999). These risks are sharply heightened by the dangers posed by the coronavirus. We urge your immediate action.

DREDF urges the following additional steps to ensure that disabled Californians are safe in their homes and communities with supports during the COVID-19 crisis:

- Ensure that accurate and up-to-date information about the progression of COVID-19 within California and worldwide is fully accessible in alternative print and online formats,
transcribed into threshold languages, and available in American Sign Language and captioned videos.

- Require all private insurers operating in California to provide fully accessible, current, clear, and readily available information about in-network and out-of-network coverage of COVID-19 testing and treatment.

- Require public utilities and internet providers to maintain gas, electricity, water, telephone, and internet services for people with disabilities sheltering in place.

- Ensure that public and private insurance prioritization of healthcare procedures consider not only the category of procedure before cancelling or delaying it as “elective/non-urgent,” but also the underlying conditions and cross-disability needs of the person who will be undergoing a scheduled procedure.

- Continue provision of ADA paratransit, NEMT, and accessible on-demand service for passengers, including trips to the grocery store, medical facilities, and COVID-19 testing sites. Maintain ADA paratransit service areas even where bus routes are cut.

- Protect passengers and workers by ensuring provision of adequate protective gear and cleaning supplies for transit workers, including NEMT providers and janitorial support staff.

- Place a comprehensive state-wide moratorium on evictions and a hold on termination of public benefits, including all administrative actions that result in individuals being cut off from public benefits.

**Ensure Legal Services and Prompt Affirmative Responses to the Potential Violations of Rights of Disabled Californians**

We ask that California take steps to bolster financial and human resources in California’s legal service organizations to ensure that they have the capacity to provide timely representation for individuals who face unlawful medical “rationing” based on disability, any unnecessary and involuntary institutionalization, and other forms of discrimination in COVID-19 treatment and testing.

We further ask that you ensure that California and its agencies respond immediately and effectively to any reports or complaints indicating that the rights of people with disabilities are being violated. While this must include prioritization and streamlining of administrative
To: Governor Newsom  
RE: Survival of People with Disabilities During COVID-19  
March 20, 2020  
Page 6 of 6

complaint procedures at the DHCS Office of Civil Rights and other agencies, we call on the Governor and the heads of relevant agencies to respond affirmatively and forcefully to any formal or informal report.

Our state has long been a leader in many aspects of healthcare, accessibility, and civil rights protections for people with disabilities. California is the birthplace of the internationally-known independent living movement. Help us to maintain our reputation as a leader in preserving the rights of people with disabilities. We would welcome the opportunity to work with your administration on ensuring that people with disabilities in our state receive equal and effective healthcare during the COVID-19 crisis under the priorities detailed above.

Sincerely,

Susan Henderson  
Executive Director

CC:  Dr. Mark Ghaly, California Health & Human Services Agency  
     Dr. Sonia Angell, California Department of Public Health  
     Dr. Bradley Gilbert, California Department of Health Care Services  
     Shelley Rouillard, California Department of Managed Health Care  
     Ricardo Lara, California Department of Insurance