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The Honorable Michael J. Dunleavy  
Governor of Alaska  
Office of the Governor  
P.O. Box 110001  
Juneau, AK 99811-0001

April 2, 2020

Dear Governor Dunleavy:

First, thank you and the many state agency and department leaders and staff for the massive efforts that you have undertaken to provide leadership and mobilize state resources to confront the COVID-19 pandemic.

We write to urge you to use your leadership and vision to take additional steps to protect the welfare of all Alaskans, but especially those with disabilities, during this crisis. As you are aware, adults and children with disabilities are among those at the greatest risk in this crisis because so many are in institutions or incarcerated, homeless, seniors or medically compromised, or dependent on others for care.

We also ask you to use your leadership to ensure that people with disabilities will not be disproportionately affected by any loss of services and benefits during the pandemic, protecting everyone in this crisis is the best public policy. As you have recognized, Alaska must ensure that all our citizens have access to a safe living situation, medical care and other resources to weather this crisis.

In the context of this pandemic, the undersigned organizations agree and strongly endorse the message that the presence of a disability should not be an indicator for withholding or limiting access to medical care. This is the position taken by Congressman Don Young in signing on to the bipartisan, bicameral letter to Secretary Alex M. Azar, Department of Health and Human Services, and to Attorney General William Barr (attached). That letter reads in part, “[w]hile we recognize that it may be appropriate for healthcare providers to delay non-essential care, life-sustaining treatments should not be denied from people with disabilities.”

A few days later, the Office for Civil Rights within the U.S. Department of Health and Human Services issued a guidance bulletin reminding covered entities of their obligations under the laws prohibiting discrimination (attached). Specifically addressing the allocation of scarce healthcare resources, OCR notes: “[P]ersons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative “worth” based on the presence or absence of disabilities. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.”

In recent days, we have grown increasingly concerned with the information regarding the healthcare treatment guidelines published related to the COVID-19 outbreak (Cha, 2020; Mounk, 2020)<sup>1</sup>. These guidelines pave the way for increased discrimination toward individuals with disabilities and older individuals who have contracted COVID-19. These discriminatory guidelines have resulted in complaints to the Office of Civil Rights. The complaints allege illegal disability discrimination that is putting the lives of people with disabilities at imminent risk during the COVID-19 pandemic. As COVID-19 cases increase, the experience in other countries and predictions of U.S. health officials is that there will not be enough acute care services or equipment, such as ventilators, to meet the demand of patients with the virus who require intensive treatment.

Health care professionals in the United States are already developing protocols for responding to COVID-19, including treatment rationing that will determine who will and will not have access to life-saving treatment. As Alaska plans for the allocation of scarce healthcare resources, we ask that such planning adhere to the following principles:

- No life is more precious than another. All people in Alaska are worth saving.
- Should medical treatment need to be rationed, it will be done in the most equitable way possible. Specific protocols must be developed to diminish implicit bias in medical decision making including:
  - Prohibiting treatment allocation decisions based on the assumption that people with disabilities experience a lower quality of life, have a lower prospect of survival, and/or will require the use of greater treatment resources;
- The State must provide guiding principles for the development of protocols for medical rationing consistent with the following:
  - Decisions regarding the allocation of treatment/life-saving resources should be made on an individual basis, using objective medical evidence and not generalized assumptions about a person’s disability;

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<sup>1</sup> Cha, A. E. (2020, March 15). Spiking U.S. coronavirus cases could force rationing decisions similar to those made in Italy, China. *The Washington Post*, Retrieved from <https://www.washingtonpost.com/health/2020/03/15/coronavirus-rationing-us/>

Mounk, Y. (2020, March 11). The extraordinary decisions facing Italian doctors. *The Atlantic*, retrieved from <https://www.theatlantic.com/ideas/archive/2020/03/who-gets-hospital-bed/607807/>

- A person is qualified to receive COVID-19 treatment if they can benefit from treatment (can recover) and the treatment is not contraindicated.
- The protocols should avoid judgments about quality of life. “Quality of life” is a relative judgement prone to a number of biases, including but not limited to disability, income, race, gender identity, and more.
- The protocol should also avoid judgments about “health status.” Many persons with disabilities are healthy but live with ongoing conditions that could be construed as “unhealthy.”
- The State of Alaska should instead establish an emergency triage treatment protocol for the entire state whose guiding principle would be an individualized assessment of each person’s likelihood to survive if offered whatever medical services are in limited supply. This assessment would be based on an individual’s specific functioning, and not upon assumptions based on a person’s pre-existing condition or specific diagnosis. If a person is likely to survive with available treatment, he/she would receive treatment. If not, he/she would not receive treatment. This standard would enable the system to deflect limited available treatment away from: (a) people who are expected to recover without such treatment, and (b) people who are not expected to recover with such treatment.

During this pandemic, it is critical to remember that individuals with disabilities, including those with significant disabilities, have the following human and civil rights:

- Access to high-quality, appropriate medical treatment
- Access to timely and accurate information in accessible formats (e.g., plain text, visuals, plain language)
- Access to supports and support persons to address the individual’s unique support needs related to social/emotional, communication, physical, and healthcare aspects.
- Access to supported decision making and representation during any emergency guardianship or conservatorship proceedings

We advise against actions concerning medical treatment that perpetuate discrimination. There is a long history of unethical practices, including eugenics and institutionalization, which has led to the dehumanization, disenfranchisement, and devaluation of the lives of individuals with disabilities. These practices have occurred in particular around access to resources and information. It is our responsibility to work with the State to ensure we do not return to these unethical practices and ensure the humanity of all individuals is maintained.

We ask that you direct DHSS to take the necessary steps to ensure that medical providers have proper guidance and to prevent the discriminatory rationing of healthcare if this important action has not already been done. If it has, we ask that the protocols be reviewed to ensure adherence to the statement of principles and rights noted above.

Respectfully,

Disability Law Center of Alaska  
University of Alaska Anchorage Center for Human Development  
Governor's Council on Disabilities and Special Education  
Alaska Mental Health Trust Authority  
Alaska Association on Developmental Disabilities  
Advisory Board on Alcoholism and Drug Abuse  
Alaska Mental Health Board  
Stone Soup Group

cc:

DHSS Commissioner Adam Crum  
DSDS Director John Lee  
U.S. Representative Don Young  
U.S. Senator Lisa Murkowski  
U.S. Senator Dan Sullivan