DISABILITY
RIGHTS
MAINE

Sent via electronic and U.S. Mail

April 7, 2020

Commissioner Jeanne M. Lambrew
Department of Health and Human Services
109 Capitol Street
Augusta, ME 04333

Dr. Nirav D. Shah, M.D., J.D.
Maine Center for Disease Control and Prevention
286 Water Street
State House Station 11
Augusta, ME 04333-0011

RE: COVID-19 and the Civil Rights of Maine Citizens with Disabilities

Dear Commissioner Lambrew and Doctor Shah:

Disability Rights Maine (DRM) is Maine's designated and mandated Protection and Advocacy organization, existing under federal law, and funded by both State and Federal government, to enforce and enhance the rights of individuals with disabilities.

On behalf of DRM, I wish to thank you for your tireless work on behalf of Mainers during this crisis. I am writing today on a truly life-and-death situation that threatens citizens of Maine who happen to have disabilities. We at Disability Rights Maine ask that you take specific steps to ensure that life-saving care is not illegally withheld from disabled citizens due to discriminatory resource allocation or altered standards of care during the coronavirus pandemic.

People with disabilities are, and will be, at high risk of contracting COVID-19, particularly those who are in congregate residential programs, institutional settings, prisons and jails, and long-term care facilities. We recognize and appreciate that Maine is already making efforts to protect the safety of these residents and we thank you. But we are hearing from our peers around the country that disability advocacy groups are seeing outdated and discriminatory policies on emergency resource allocation in which individuals with specific disabilities or functional impairments can be denied access to,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.

The law in this area is clear. All public 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. While we recognize the need to plan and be prepared for healthcare resource shortages during these times, the guiding standards that the State of Maine adopts must be consistent with federal law, and must ensure that "persons with disabilities… not be put at the end of the line for health services during emergencies."[1]

It is our understanding that the State of Maine is developing crisis standards of care to guide the allocation of health resources should the worst-case scenario actualize.

We ask that Disability Rights Maine be included in this discussion to ensure that the state does not adopt standards of allocation that inadvertently discriminate against people with disabilities in violation of law. If these standards or policies are already drafted, we ask for the opportunity to review and provide feedback, prior to their implementation.

As self-advocates expressed in the attached letter to Governor Mills, people with disabilities in Maine already face challenges in accessing medical care when society isn't in the midst of a pandemic. Without clear, non-discriminatory standards for allocating healthcare resources, there is a real concern that during this emergency, these challenges will be heightened and that biases against people with disabilities could influence life or death healthcare decisions about who gets treatment and who doesn't.

To ensure that standards of allocation are non-discriminatory, we ask that you issue a strong statement to health care entities instructing them that they must abide by the following principles:

- Standards of care must not contain any categorical exclusions from care based on illness, diagnosis, or pre-existing conditions.
- 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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[1] The Office for Civil Rights recently issued a bulletin reinforcing the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act. Their statement reminds healthcare providers and emergency management planners that these laws enforcing civil rights remain in effect, even during the COVID-19 pandemic. This bulletin can be found here: https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf.

- Standards of allocation must not consider judgments about "quality of life." "Quality of life" is a subjective judgment that has long been a pretext for denying treatment, including life-sustaining treatment, to people with disabilities.
- Standards of allocation must not consider judgments about "health status." Many persons with disabilities are healthy but live with ongoing conditions that could be construed as "unhealthy."

Absent these principles, individual hospitals and health care professionals are in danger of making decisions that will result in the rationing of resources in a discriminatory manner. These decisions will have irreversible consequences on the lives of people with disabilities and on society as a whole.

As Governor Mills and Dr. Shah have so clearly indicated in recent press briefings, we are on the possible verge of a statewide crisis in access to care. While there is still a window of opportunity, now is the time for Maine to act to establish equitable, democratic and nondiscriminatory standards of care before scarcity begins driving medical decisions across the state.

DRM stands ready to assist in these efforts. At a minimum, I ask that you confirm receipt of this letter regarding discriminatory rationing of care so that DRM may assist you in getting the word out into the disability community that Maine is taking seriously this grave concern of the disability community. You may contact me directly at 754.0015 or at kim@drme.org.

Thank you in advance for your consideration of this important matter.

Sincerely;

Kim Moody
Executive Director
Disability Rights Maine

CC: Maine Hospital Association, Maine Hospitals
Encl.: Letter from Speaking Up For Us to Governor Mills, sent April 1, 2020

April 1, 2020

Re: Speaking Up For Us Self-Advocate Concerns Regarding Disability Discrimination During COVID-19 Treatment

Dear Governor Mills,

First, we would like to thank you for your quick action in making difficult decisions for the safety of all Mainers since the beginning of the COVID-19 pandemic. You and your team have been working very hard to limit the spread of this virus and ease the burden on our healthcare system in Maine.

Speaking Up For Us (SUFU) is Maine's Self-Advocacy Network for people living with Intellectual and Developmental Disabilities (I/DD). Self-Advocacy is part of the civil rights movement for people living with I/DD to advocate and voice their experiences and opinions on issues that are important to them. Self-Advocates have been organized and advocating for the rights of people living with I/DD in Maine since 1993.

SUFU is sharing this statement about the real concerns of self-advocates during a very difficult time in our country. COVID-19 is infecting people in all 50 states and health care systems are becoming overwhelmed. There is a shortage of medical supplies that are used to protect health care workers and other workers who are at risk of getting this virus. The medical supply shortage includes not having enough life-saving equipment like respirators available. Many state governments are putting "Stay at Home" orders in place.

SUFU has real concerns that due to the shortage of life saving supplies like respirators, health care providers may be forced to make difficult medical decisions based up deciding quality of life of sick patients. This means that a healthcare provider could have to make life or death decisions based on what type of treatment is available. SUFU feels that these decisions could discriminate against people living with disabilities. People living with I/DD already have challenges accessing medical care when our society is not faced with a pandemic. There is real concern that disability could be used in determining which sick person is put on a ventilator.

Very recently, Sarah, a self-advocate from Sabattus, experienced this type of discrimination during a routine medical test. "It is very difficult for me to get a mammogram because I do have some physical limitations. When I recently went to get one, the technician had a hard time and then told me that maybe I shouldn't get any more mammograms due to my disability. This really upset me, because my sister has had breast cancer. I was able to find a different healthcare facility that performed the test with no problems and my mom came with me to help." Sarah's experience demonstrates the reality for many people living with disabilities in Maine.

Historical treatment of people with disabilities shows how easy it is to devalue people based upon their disability. Marco, a self-advocate from Brewer Maine shares, "No one should be made to feel like they are expendable in a situation like this. Historically, people with disabilities have been left to fend for themselves in a time of emergency. People with disabilities should be more of a priority, and less of an option to society."

The Office of Civil Rights recently issued a bulletin reinforcing the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act. Their statement reminds healthcare providers and emergency management planners that these laws enforcing civil rights remain in effect, even during the COVID-19 pandemic. This bulletin can be found here: https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf.

As more information is learned about COVID-19, it appears that this virus puts people with compromised immune systems and pre-existing medical conditions in a higher risk category. People living with disabilities are significantly more likely to fall into this higher risk category. SUFU believes that because of this increased risk, people with disabilities should be prioritized in testing and prevention efforts. Kile, a self-advocate from Fort Kent states "We should not be pushed aside and not be provided care because we have a disability. No doctor should make a last-minute decision to not give us life-saving care based on a disability."

SUFU has seen that several states across the country are developing guidelines for deciding how ventilators are to be used due to the shortage. As of today, the Maine CDC has not yet published any guidelines on their COVID-19 website about ventilator use decisions. SUFU would encourage the following be used in the development of any ventilator use guidelines:

1. Treatment decisions should be made on an individual basis, using current medical information, and not based on assumptions about a person's disability.
2. Treatment decisions should not be made using assumptions that a person with a disability has a lower quality of life or assume that their life is not worth living.
3. Treatment decisions should not be made based on assumptions that a person with a disability has a lower survival rate because of their disability.
4. Treatment decisions should not be made based on assuming that a person with a disability will need greater resources to provide treatment.
5. Reasonable accommodations should be made to ensure that people with disabilities have an equal opportunity to get treatment.

SUFU will work with its disability advocacy partners to make sure that people with disabilities are not discriminated against during the COVID-19 pandemic. We will advocate and educate lawmakers, healthcare providers, and others to be inclusive in providing testing and treatment regarding COVID-19. We urge Maine lawmakers and healthcare providers to put practices in place to make sure discrimination during treatment of COVID-19 will not happen for people living with disabilities.

We would ask you, as our Governor to issue a strong statement to healthcare workers to consider their assumptions about people living with disabilities. We would also ask you to bring the ventilator use guidelines we are recommending forward to be used in any communications with healthcare workers or Maine CDC guidelines that may be published for use in the future.

Hope, a self-advocate from Fort Fairfield stated, "We are more than what other people can ever see of us." SUFU will continue to bring forward the rights of people living with disabilities until we are seen and heard.

Sincerely,

Self-Advocates from Speaking Up For Us

cc: Jeanne Lambrew, DHHS Commissioner
Dr. Nirav Shah, Director Maine CDC
Paul Saucier, Director Office of Aging and Disability Services

Disability Network Partners Include:

DISABILITY RIGHTS MAINE

Maine Developmental Disabilities Council
Advocacy ~ Capacity Building ~ Systems Change

1865 THE UNIVERSITY OF MAINE
Center for Community Inclusion and Disability Studies
University Center for Excellence in Developmental Disabilities

For more information from Speaking Up For Us please contact:
Monique Stairs, Interim Executive Director
PO Box 4139
Presque Isle, ME 04769
(207) 956-1004
Email: programsufu@sufumaine.org
Website: http://sufumaine.org/