



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:



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