



PROTECTION & ADVOCACY
SERVICE, INC.

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April 24, 2020

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Hon. Dana Nessel
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G. Mennen Williams Building
525 W. Ottawa Street
P.O. Box 30212
Lansing, MI 48909

**RE: Michigan's Need for Non-Discriminatory Guidance on
Rationing Scarce Medical Resources in the COVID-19 Pandemic**

Dear Governor Whitmer and Attorney General Nessel:

At the outset, we do want to take this opportunity to commend and thank you for your overall efforts to fight this crisis to protect the health and welfare of the residents of the State of Michigan.

This letter represents the collective voice of 19 disability rights organizations/individuals that desire to present concerns about the guidance from the State of Michigan regarding appropriate and ethical actions that healthcare providers are to take when making decisions about medical treatment during the COVID-19 pandemic.

We wish to inform you of serious concerns on behalf of people with disabilities in Michigan regarding their civil rights and equal access to potentially scarce resources in this pandemic crisis, including

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ventilators. **Current guidance adopted by the State will have a discriminatory effect on people with disabilities and pre-existing conditions which must be rescinded.** Michigan has implemented the *COVID-19 Practice Management Guide*, adapted from the Department of Defense and Minnesota Department of Health, which provides guidance to health care infrastructure that is discriminatory against people with disabilities.¹ This document guides healthcare infrastructure on what to do in the event medical resources become scarce.² The most notable example of discriminatory guidance is found in Appendix H, which details “strategies for scarce resource situations.”³ Most concerning is the guidance related to mechanical ventilation which includes prioritizing reallocation of life saving ventilation equipment based on disability, rather than an individualized assessment of whether the patient can benefit from treatment.⁴ Under the current guidance, in order to be designated as having a “low potential for death” a patient cannot have a “severe underlying disease.”⁵ While consideration of underlying conditions is permissible as part of an objective, individualized assessment; de-prioritization based solely on an underlying diagnosis is discriminatory. As an example, an individual “requiring continuous oxygen use prior to the onset of acute illness” would be immediately de-prioritized under this guidance without requiring an individual assessment as to their ability to benefit from treatment.⁶

Additionally, those individuals who may require a greater duration of need are given lower priority in the determination of who receives a ventilator, which disproportionately affects people with disabilities.⁷ Treatment allocation decisions should not be made based on the perception that a person’s disability will require the use of greater treatment resources and should be based on an objective, individualized assessment. Further, the *COVID-19 Practice Management Guide* references the *Fair Allocation of Scarce Medical Resources in the Time of Covid-19* published in *The New England Journal of Medicine*.⁸ This article encourages making scarce medical resource allocation decisions that save the most life-years in allocating scarce medical resources.⁹ Prioritization based on life-years disproportionately affects people with disabilities due to stereotypes and subjective assumptions about certain diagnoses. Medical resource allocation decisions should be made based on how to save as many people that can benefit from treatment rather than, for example, prioritizing the younger over the older.

The Office for Civil Rights of the Department of Health and Human Services has declared that “persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgements about a person’s relative ‘worth’ based on the presence or absence of disabilities.” The *COVID-19 Practice Management Guide* violates this mandate.

¹https://www.michigan.gov/documents/coronavirus/COVID19_Practice_Management_Guide_Final_685523_7.pdf

² *Id.* at 33-34, 38-39, 58, and 71.

³ *Id.* at 58.

⁴ *Id.* at 71.

⁵ *Id.*

⁶ *Id.*

⁷ *Id.*

⁸ *Id.* at 34, 39, and 44.

⁹ *See* Recommendation 1 and 4.

Disability rights advocates have written letters to the State as early as March 23, 2020 and as recently as April 10, 2020 regarding medical rationing issues.¹⁰ Still, Michigan has failed to address the March 28, 2020 Bulletin from the HHS Office of Civil Rights; therefore, we believe it is our obligation, on behalf of all persons with disabilities in Michigan, to urgently request the inappropriate policy guidance contained in the *COVID-19 Practice Management Guide* be rescinded with notice provided to all healthcare entities and new guidance be issued that clearly advises hospitals to perform an individualized assessment of all patients when making resource reallocation decisions. Upon rescinding the problematic language, Michigan should work towards releasing additional guidance that complies with the principles and values outlined by Michigan Protection & Advocacy Service, Inc.'s correspondence to MDHHS' Department of Legal Affairs on March 29, 2020¹¹ and HHS' March 23, 2020 Bulletin.

From our perspective, having appropriate policy guidance on medical rationing is long overdue and critically necessary in order to prevent people with disabilities from unnecessarily being denied access to life-saving medical treatment by virtue of having a disability.

Even if we have reached the apex of hospital admissions and new cases, the State's response and action is urgently needed to save the lives of people with disabilities going forward. As we all know, the models are based on incomplete testing and the down-slope of the curve will likely have just as many or more deaths as the up-slope.

The guidance issued in Michigan will have a discriminatory impact on people with disabilities when determining how to provide and withdraw scarce life-saving resources.

This letter reiterates the request for a policy that protects the rights of persons with disabilities seeking medical care and treatment under any circumstance. Michigan ranks third in total deaths 2,977 and fourth in total cases of 35,291 nationwide as of April 24, 2020. This issue requires a formal response in the form of an Executive Order that explicitly states that civil rights are non-negotiable, rescinds the problematic aspects of *COVID-19 Practice Management Guide* identified above, and creates a policy in compliance with guidance issued by the United States Department of Health and Human Services.

Additionally, data shows that there is a disproportionate impact of COVID-19 upon older individuals, the African American community, and other communities of color. For people of color with disabilities, in particular, the risk of contracting COVID-19 and then facing challenges accessing healthcare and treatment are increased. People at the intersection of these identities are rightfully fearful of discrimination, stereotypes, and assumptions by medical providers based on one or several of their marginalized identities.

Disability is a key social characteristic that cuts across race, ethnicity, gender, national origin, sexual orientation, and religious affiliation, but it does not appear to be tracked by the state as

¹⁰ April 1 and April 10, letters from Dessa Cosma, Detroit Disability Power and March 23, 2020 letter from Sam Bagenstos.

¹¹ See Exhibit 1.

part of the COVID-19 response. It should be. Hospitals record comorbidities and pre-existing conditions, and if we track disability, we can explore correlations across social characteristics as well as solutions.

The signatories to this letter request immediate action and a response detailing the steps Michigan will take to ensure people with disabilities have equal access to healthcare in the event of scarcity.

We are looking forward to your response and working with you in any way we can to achieve these goals.

Thank you for your attention and consideration.

Sincerely,

Michigan Protection and Advocacy Service, Inc.	Mental Health Association in Michigan
Autism Alliance of Michigan	MHAM
Michigan Disability Rights Coalition	The Arc of Michigan
Michigan Developmental Disabilities Council	Detroit Disability Power
National Alliance on Mental Illness – Michigan	American Civil Liberties Union of Michigan
Samaritas	Shannon DeWall, Disability Rights Attorney
Nadia Vann, Disability Rights Attorney	Michael Bartnik, Disability Rights Attorney
Christine Caswell, Disability Rights Attorney	Jill Babcock, Disability Rights Attorney
Sam Bagenstos, Attorney	Jenny Thomas

Jan Lampman

cc: Lt. Governor: Garlin.Gilchrist@michigan.gov
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EXHIBIT

1

From: KYLE WILLIAMS

Sent: Tuesday, March 31, 2020 9:33 PM

To: AsmanL@michigan.gov

Cc: Samuel Bagenstos <sbagen@gmail.com>; Merissa Kovach <mkovach@aclumich.org>;

MARK MCWILLIAMS <mmcwilliams@mpas.org>

Subject: Joint Document Regarding Medical Rationing

Leslie,

Thanks for taking the time to discuss this matter with me. As you know, MPAS has been working with the ACLU and Sam Bagenstos to create guiding principles and values for addressing the event of medical rationing in Michigan. While we all feel there is a need for much greater guidance regarding the protocols for ensuing these principles and values are implemented, we have an opportunity to communicate our position on medical rationing jointly with the State. We are hopeful the State's principles and values are the same as ours and would like to work on a joint document reflecting the following principles:

- No life is more precious than another. All people in Michigan are worth saving.
- The ADA, PWDCRA, ACA, and Section 504 of the Rehab Act all provide that a person with a disability cannot be discriminated against on the basis of disability.
- Individuals with disabilities are entitled to reasonable accommodations in order to allow access to care.
- Should medical treatment need to be rationed, it will be done in the most equitable way possible. Specific protocol 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;
 - A person is qualified to receive COVID-19 treatment if they can benefit from treatment (can recover) and the treatment is not contraindicated.
 - The protocol 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." For example, in Alabama, its current triage system chillingly denies life-saving services to those with a diagnosis of AIDS, with severe developmental disability, and those with renal failure requiring dialysis. Similarly, in Tennessee, its system wrongly excludes individuals from treatment if they experience advanced untreatable neuromuscular disease (such as ALS, end-stage MS, spinal muscular atrophy) and require assistance with activities of daily

- living or chronic ventilator support. Finally, the State of Washington is considering a reliance on “health” factors among other criteria in its triage system.
- The State of Michigan 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.

As mentioned above, we all feel there is a need to develop more specific guidance on protocols that will implement these principles. We also request a work group be formed to create protocols with representation from the State, hospitals and doctors, people with disabilities, and advocacy organizations.

Thank You for your attention to this important matter. I hope to hear from you soon with MDHHS’ response.

Regards,

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