



BY ELECTRONIC DELIVERY

March 26, 2020

J.B. Pritzker, Governor
Sol Flores, Deputy Governor
Dr. Ngozi Ezike, Director of the Illinois Department of Public Health
Theresa Eagleson, Director of the Illinois Department of Healthcare and Family Services
Grace Hou, Secretary of the Illinois Department of Human Services

Re: Prospect of Rationing Life-Sustaining Treatment During the COVID-19 Crisis

Dear Governor Pritzker, Deputy Governor Flores, Director Ezike, Director Eagleson, and Secretary Hou:

As you have discussed publicly, there is deep and growing concern that the health care system in Illinois lacks sufficient acute care services and equipment, such as ventilators, to meet the demand of patients with COVID-19 who require intensive treatment. In response, many health care systems are being forced to develop protocols to ration life-saving treatment. To put it plainly, health care professionals are being asked to determine who will and who will not be provided life-sustaining and life-saving treatment – basically, who will live and who will die.

Like many in Illinois, Access Living, along with the undersigned organizations, have been grateful for Governor Pritzker's strong pronouncements during this crisis about the sanctity of all lives, including his statement yesterday that "[t]here is no life in this state that is more or less precious than any other. No person more or less worthy of saving." Those stirring words are especially critical at this time and we – along with our partners and the many people with disabilities we serve – appreciate that sentiment.

The Governor's comments were especially timely. On Monday and Tuesday of this week, disability advocates filed federal complaints regarding rationing-type policies in health systems in [Washington State](#) and [Alabama](#). The community concern about this problem is snowballing. These complaints demand that the U.S. Department of Health and Human Services Office of Civil Rights issue guidance for emergency protocols that eliminate bias against people with disabilities.

As a disability rights organization, we write to drive home two major concerns about the rationing of intensive treatment based on protocols, and urge the state to convene an emergency

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task force charged with developing an equitable protocol for rationing that respects the dignity of people with disabilities.

- First, unless the protocols are carefully developed and implemented, they are likely to violate federal civil rights laws that prohibit discrimination against people with disabilities, including the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act (Section 504), and Section 1557 of the Affordable Care Act (ACA).
- Second, and relatedly, it is possible to develop protocols that ration care as equitably as possible, and diminish the chances that implicit bias will significantly influence what should otherwise be sound and fair medical decisions. This subsequently frees medical professionals from the stress and burden placed on them when tasked with implementing those protocols, and strengthens patient and community trust and confidence in their medical providers.

To assist the State of Illinois to establish an equitable protocol, this letter (a) provides background for our concerns, (b) outlines the guiding principle of a model protocol, and (c) urges the establishment of an emergency task force to develop a protocol the state would mandate for adoption and implementation by medical providers in Illinois.

Background: History of Disability Discrimination and Bias in the Medical Community

Studies have repeatedly documented a persistent bias on the part of medical providers against people with disabilities and, notably, a persistent failure of medical providers to fully appreciate the value and quality of life with a disability.¹ These problems are reinforced by the dramatic underrepresentation of disabled people in the health professions.

Discrimination is not always driven by malice. It is often so ingrained in the thought process of the medical professionals that they do not notice they are discriminating against people with disabilities. In the case of medical discrimination, often the discriminating provider claims he or she simply tried to do what was in the patient's best interest, and does not view the actions that were or were not taken as discriminatory. Nonetheless, many people with disabilities who seek treatment are denied treatment based on implicit biases about the quality of life and inherent worth of people with disabilities.²

High stakes medical decisions are some of the most difficult choices made by healthcare professionals. However, healthcare decisions are influenced by more than just medical facts.

¹ See, e.g., David Carlson, Cindy Smith, Nachama Wilker, Devaluing People with Disabilities: Medical Procedures that Violate Civil Rights, National Disability Rights Network and Disability Rights Washington p.40 (2012), http://ndrn.org/images/Documents/Resources/Publications/Reports/Devaluing_People_with_Disabilities.pdf.

² *Id.*

Instead, innumerable social factors influence these decisions, as well as time, expertise, finances, supplies, and other factors. When stakes are high and resources are low, medical decisions can especially be influenced by a patient's race, gender, sexuality, age, religion, citizenship, and financial background in ways that can both be detrimental and unfairly prejudicial to a person's well-being. Disability status is also an important factor that influences the decisions of medical professionals providing life-sustaining health care.³

It is not hard to see how negative views of disability persist in the medical community.⁴ Last fall, the National Council on Disability released a series of reports about numerous problems with the way bioethics and the medical profession at large relate to people with disabilities.⁵ A recent medical study similarly showed open hostility to people with disabilities by a large segment of the medical community who refuse even to treat patients with disabilities.⁶ A quarter of doctors in the study refused to schedule an appointment with potential patients who used wheelchairs.⁷ Another recent survey confirmed that physicians “demonstrated superficial or incorrect understanding” of the ADA and other anti-discrimination laws.⁸

Research has shown that disabled patients “experience health care disparities, such as lower rates of screening and more difficulty accessing services, compared to people without disabilities.”⁹ Medical professionals have historically deprioritized the delivery of treatment to people with disabilities due to their negative views, which continue to make it more difficult for people with disabilities to get treatment. Now, without the state's affirmative action, these historic problems will lead to the denial of life-sustaining services to people with disabilities during this pandemic.

³ See e.g., Okoro CA, Hollis ND, Cyrus AC, Griffin-Blake S., *Prevalence of disabilities and health care access by disability status and type among adults—United States, 2016*. MMWR Morb Mortal Wkly Rep. 2018; 67(32):882–7.

⁴ This medical bias against disability is not isolated to the United States and its medical institutions, the same study was conducted simultaneously in Spain with similar results were found. Brian Skotko, *Mothers of Children with Down Syndrome Reflect on Their Postnatal Support: An International Call for Change*, Italian Journal of Pediatrics 237-245 (2005).

⁵ National Council on Disability, “Bioethics and Disability Report Series,” (2019) <https://ncd.gov/publications/2019/bioethics-report-series>

⁶ Pauline W. Chen, “Disability and Discrimination at the Doctor's Office,” The New York Times (May 23, 2013), <https://well.blogs.nytimes.com/2013/05/23/disability-and-discrimination-at-the-doctors-office/>, citing Lagu T, Hannon NS, Rothberg MB, et al. *Access to Subspecialty Care for Patients With Mobility Impairment: A Survey*. Ann Intern Med. 2013; 158:441–446. doi: <https://doi.org/10.7326/0003-4819-158-6-201303190-00003>

⁷ *Id.*

⁸ Nicole D. Agaronnik, Elizabeth Pendo, Eric G. Campbell, Julie Ressler, and Lisa I. Iezzoni, *Knowledge Of Practicing Physicians About Their Legal Obligations When Caring For Patients With Disability*, HEALTH AFFAIRS VOL. 38, NO. 4: PHYSICIANS, MEDICARE & MORE (April 2019), <https://doi.org/10.1377/hlthaff.2018.05060>

⁹ Iezzoni LI. *Eliminating health and health care disparities among the growing population of people with disabilities*. Health Aff. (Millwood). 2011;30(10):1947–54.

Model Protocol

We acknowledge that during the type of emergency triage faced by medical professionals in the current crisis, some people with disabilities may be unlikely to survive, even if triage is practiced in a truly equitable manner. Our aim is for the State of Illinois to develop a protocol that (a) emphasizes and maximizes equity, (b) eliminates disability bias (and its intersections), and (c) minimizes the impact of social inequalities on medical decisions and health outcomes. With those goals in mind, we recommend the following guideposts for a state-issued emergency triage protocol:

- 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.¹⁰ 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.¹¹ Finally, the State of Washington is considering a reliance on “health” factors among other criteria in its triage system.¹²
- The State of Illinois 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. If, after implementing the guiding principle, available treatment resources remain

¹⁰ See *Criteria for Mechanical Ventilator Triage Following Proclamation of Mass-Casualty Respiratory Emergency*, at <http://www.adph.org/CEP/assets/VENTTRIAGE.pdf>, last viewed March 24, 2020.

¹¹ See *Guidance for the Ethical Allocation of Scarce Resources during a Community-Wide Public Health Emergency as Declared by the Governor of Tennessee*, at https://www.tn.gov/content/dam/tn/health/documents/2016_Guidance_for_the_Ethical_Allocation_of_Scarce_Resources.pdf, last viewed March 24, 2020.

¹² See *Complaint of Disability Rights Washington*, at https://www.centerforpublicrep.org/wp-content/uploads/2020/03/OCR-Complaint_3-23-20-final.pdf, last viewed March 24, 2020.

insufficient to meet demand, then the state could mandate that services be (a) provided on a first come, first served basis, or (b) if a first-come first-served system is undesirable, based on a set of secondary principles that ensure equitable decision-making. In any event, with the guiding principle as a starting point, we urge the Governor to convene an emergency task force to develop the treatment protocol, and we would be honored to be a part of it.

Assumptions about the quality of life or health of people with disabilities are burdened by centuries of bias. The effect of acting in compliance with such biases will be to discriminate based on disability, and negatively impact the ability of people with disabilities to receive treatment. Accordingly, the state must establish a protocol to remove such biases from the triage system.

Conclusion

We, along with the undersigned organizations, look forward to your response to this letter, and urge the establishment of an emergency task force to help the state establish protocols that: (a) are as equitable as possible to those in need of life-saving treatment, and (b) alleviate the tremendous burden placed on health care professionals who will rely on the protocols to make life or death decisions. For further information, please contact Karen Tamley, President and CEO of Access Living.

We thank you for your leadership during this evolving COVID-19 crisis, and your serious consideration of this proposal.

Sincerely,

A+ Autism Solutions
Access Living
Achieving Independence and Mobility Center for Independent Living (AIM-CIL)
ACLU of Illinois
ADA 25 Advancing Leadership
Ada S. McKinley Community Services Inc.
Advocates for Access
AgeSmart Community Resources
AIDS Foundation of Chicago
Alderman Byron Sigcho Lopez
Alderman Michael Rodriguez
Alderman Andre Vasquez
Alderwoman Maria Hadden
Alliance for Community Services
Anixter Center
Arts of Life

Asian Americans Advancing Justice|Chicago
Avancer Homes LLC
Avenues to Independence
Birchwood Interiors
Blue Cap
Boot Books
Butterflies for Change
Caring Across Generations
CCAR Industries
Center for Changing Lives
Center for Enriched Living
Center for Independent Futures
Central Illinois Service Access
Champaign County Developmental Disabilities Board
Champaign County Health Care Consumers
Champaign County Mental Health Board
Chicago Area Fair Housing Alliance
Chicago Housing Initiative
Chicago United for Equity
Chicagoland Disabled People of Color Coalition
CHS (Chicago Hearing Society)
Citizen Action/Illinois
Clearbrook
Community Alternatives Unlimited
Community Choices
Community Service Center of Northern Champaign County
DIANE HOME CARE, INC.
Disability Dental Services
Disability Resource Center
disABILITY Resource Expo - Champaign County Mental Health Board
Don Moss & Associates
Dorr-Wood Ltd
DuPage Valley Special Athletes (DVSA)
Easter Seals Chicago
Encore Developmental Services
Equip for Equality
EverThrive Illinois
Family Voices of Illinois
Gateway To Learning
HIGH IMPACT Mission-based Consulting
Human Service Transportation Planning
IARF
Illinois Alliance for Retired Americans

Illinois Assistive Technology Program
Illinois Assoc. of Microboards & Cooperatives (IAMC)
Illinois Council on Developmental Disabilities
Illinois Network of Centers for Independent Living (INCIL)
Illinois Parents of Adults with Developmental Disabilities United
Illinois Partners for Human Services
Illinois Self Advocacy Alliance
Illinois Valley Center for Independent Living
IMPACT CIL
Individual Advocacy Group
Institute on Disability and Human Development
Institute on Public Policy for People with Disabilities
JCFS Chicago
Jewish United/Jewish Federation of Metropolitan Chicago
Kenwood-Oakland Community Organization
Keshet
Lake County Center for Independent Living
Lambs Farm
LEEDA Services of Illinois, Inc.
Legal Council for Health Justice
LIFE Center for Independent Living (LIFE CIL)
LINC, Inc.
Livingston County Mental Health Board
Loyola University
McManus Consulting/Disability Services
Milestones
Misericordia
Mosaic
MUSE Community + Design
NAMI Champaign County
NAMI Illinois
National Council on Independent Living
National Kidney Foundation of Illinois
NSSEO
O'Koon Psychology Group
Open Communities
Opportunities For Access (OFA CIL)
Options Cil
Orchard Village
Pam Heavens - private citizen
Parents 4 Teachers
Paula L. Cantor Tutoring

Physicians for a National Health Program Illinois
Pilsen Alliance
Planned Parenthood of Illinois
Potter Bolanos
Progress Center for Independent Living
Raise Your Hand
Rave, Inc
Ray Graham Association
Resilience
Rimland Services
Riverside Foundation
Rosecrance
SEIU Healthcare Illinois Indiana
Service, Inc. of Illinois
Shriver Center on Poverty Law
Southeastern Illinois Area Agency on Aging
Southern Illinois Association for Rehabilitation Facilities (SIARF)
Southern Illinois Case Coordination Services
Southern Illinois Center for Independent Living
Springfield Center for Independent Living
St. Coletta of Wisconsin
Streator Unlimited, Inc.
The Arc of IL - Family Support Network
The Arc of Illinois
The Douglas Center
The HANA Center
The Kennedy Forum Illinois
The Network
Thresholds
Trauma & Resilience Initiative
Trilogy
Trinity Services
UCP Seguin of Greater Chicago
United Parent Support for Down Syndrome
Uniting Pride of Champaign County
West Central Illinois Center for Independent Living
Westside Justice Center
Working Family Solidarity