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1500 Union Ave., Suite 2000, Baltimore, MD 21211
www.DisabilityRightsMD.org

April 9, 2020

Honorable Larry Hogan
Governor of the State of Maryland
100 State Circle
Annapolis, MD 21401
Sent via first class mail and e-mail

Dear Governor Hogan:

Thank you for your considerable efforts to address the crisis facing our state due to the coronavirus. As the virus is expected to intensify over the next few weeks or longer, we write to request the State of Maryland adopt a policy that clearly directs medical providers throughout the State to refrain from discriminating against people with disabilities in the provision of treatment during the Coronavirus (COVID-19) emergency. Federal disability rights laws—including the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act—broadly protect people with disabilities against discrimination in receiving medical treatment. These laws apply to hospitals experiencing a medical equipment, bed, or staffing shortage during the COVID-19 pandemic as well as state policies concerning how resources should be allocated in the event of such shortages. Direction is needed to ensure equal access to ventilators and other treatment, and to prevent the unlawful deprivation of life based on disability status. Ableism must not direct our response to this crisis. Our nation’s history of discrimination in health care for persons with disabilities must be recognized as continuing to impact healthcare decisions and biases, and must be addressed. People with disabilities must not be denied treatment or deprioritized for coronavirus (COVID-19) care under medical triage or crisis standards currently under development or already being implemented.

The United States Department of Health and Human Services, Office of Civil Rights (OCR) issued guidance on Saturday, March 28, 2020¹ making it clear that treatment decisions that are based on anything other than individualized assessments run afoul of federal disability rights laws. As OCR states: “[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.”

On April 3, 2020 over ninety disability civil rights organizations signed onto a letter giving further clarification to OCR’s guidance (see attached). In order to avoid discriminatory treatment and life-threatening harm, we urge you to adopt affirmative policies reflected in the attached

¹ U.S. Department of Health and Human Services, Office of Civil Rights, BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19), March 28, 2020. Available at : <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>

letter, and to ensure that these broad principles of non-discrimination and equal treatment are part of any plan addressing allocation of scarce resources during the COVID-19 pandemic. *Specifically, we request policies state that:*

- People with disabilities must have an equal opportunity to receive life-sustaining treatment.
- Doctors and triage teams must assume that they are not free from bias in making critical treatment decisions. Value judgments about the fact that a patient may require minimal or extensive support in activities of daily living, uses augmentative or alternative communication, has a sensory disability such as blindness or is deaf or hard of hearing, uses a wheelchair, or experiences a psychiatric disability are irrelevant to decisions about whether such individuals can respond to and benefit from treatment.
- Doctors or triage teams must perform a thorough individualized review of each patient and must not assume that any specific diagnosis is determinative of prognosis or near-term survival without an analysis of current and best available objective medical evidence and the individual's ability to respond to treatment. This means that the mere fact that a patient may have a diagnosis of, for example, intellectual disability, autism, cystic fibrosis, diabetes, spina bifida, spinal muscular atrophy, neurological disorder or schizophrenia cannot be a basis (in part or whole) for denying care or making that person a lower priority to receive treatment.
- People with disabilities regularly outlive the prognoses doctors ascribe to them, often by decades. Doctors must not assume that any specific diagnosis or disability indicates a poor prognosis for near-term survival or an inability to respond to treatment. Protocols which equate survival with "health" or the absence of chronically debilitating symptoms will be discriminatory.
- Doctors and triage teams must not reallocate ventilators of individuals with disabilities who use ventilators in their daily lives and come to the hospital with symptoms of COVID-19. Individuals with disabilities who use ventilators in their daily lives should be allowed to continue to use this personal equipment if they receive COVID-19 treatment at a hospital. We must not discourage people from seeking treatment.
- Reasonable modifications must be made where needed by a person with a disability to have equal opportunity to benefit from the treatment. These include interpreter services, access to nonvisual information or other modifications or additional services needed due to a disability. They also include permitting a person to continue using a ventilator for additional time where an underlying disability means that additional time is necessary for recovery.
- Assumptions should not be made about who is immunosuppressed, including individuals with HIV/AIDS, without an individualized review of each patient.

As one national advocacy organization writes:

Disability nondiscrimination law prohibits covered entities from both treating an individual with a disability differently because of their disability or engaging in practices that disproportionately

harm people with disabilities. Notably, as recognized by the Supreme Court, Congress intended disability nondiscrimination protections to reach not only discrimination that is the result of “invidious animus,” but also of “thoughtlessness,” “indifference,” and “benign neglect.” [See Alexander v. Choate, 469 U.S. 287, 295–96 (1985)].

The implementing regulations make clear that illegal discrimination includes providing “an aid, benefit, or service that is not as effective in affording equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement” as that provided to people without disabilities [28 C.F.R. § 35.130(b)(1)(iii) (2010)]; and also “eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities from fully and equally enjoying any service, program, or activity.” [Id. § 35.130(b)(8)]. No provision in the ADA, Section 504, or Section 1557 of the ACA—nor in any other federal law—authorizes the waiver of these requirements during a public health emergency.”

Disability Rights Education and Defense Fund (DREDF)²

We have a responsibility to protect all Marylanders. By adopting the above statements and principles for use in any approved treatment protocols, Maryland can ensure that critical medical treatment is equally accessible to all. Please feel free to contact Lauren Young, lauren@disabilityrightsmd.org (410-727-6352 ext 2498) for questions or clarifications.

With appreciation for your efforts and actions on this matter,

Sarah Basehart, Director
Independence Now
ssorensen@innow.org

Michael Bullis
Executive Director
Image Center, Inc.
mbullis@imagemd.org

Katie Collins-Ihrke, MBA, MS
Executive Director
Accessible Resources for Independence
kihrke@arinow.org

Kate Farinholt, Executive Director
NAMI Maryland, National Alliance on Mental Illness
ed@namimd.org

Gail Godwin
Executive Director

² DREDF, “Preventing Discrimination in the Treatment of COVID-19 Patients: The Illegality of Medical Rationing on the Basis of Disability,” March 25, 2020.

Shared Support Maryland, Inc.
gail@shedsupportmd.org

David Greenberg
President & CEO
The League for People with Disabilities, Inc.
DGreenberg@leagueforpeople.org

Laura Howell
Executive Director
Maryland Association of Community Services (MACS)
lhowell@macsonline.org

Susan Kadis, Chair
PAIMI (Protection and Advocacy for Individuals with Mental Illness) Council
Advisory Council for Disability Rights Maryland
sdeek2453@gmail.com

Ande Kolp
Executive Director
The Arc Maryland
akolp@thearcmd.org

Rachel London, Esq.
Maryland Developmental Disabilities Council
RLondon@md-council.org

Dan Martin
Senior Director of Public Policy
Mental Health Association of Maryland
dmartin@mhamd.org

Dale Meyer, President/CEO
People Encouraging People, Inc.
DaleM@peponline.org

[Robin Murphy](mailto:robinm@disabilityrightsmd.org)
Executive Director
Disability Rights Maryland
robinm@disabilityrightsmd.org

Ronza Othman, President
National Federation of the Blind of Maryland
president@nfbmd.org

Maureen Van Stone, Esq., MS
Director
Maryland Center for Developmental Disabilities
vanstone@kennedykrieger.org

Edward Willard
Advocate for Citizens with Disabilities
ewillardjr@gmail.com

Floyd Hartley
hartleyfloyd_ssf@yahoo.com

William Fields
wbir@aol.com

Crosby King
Crosbyking77@gmail.com

Michael Gerlach
michaelegerlach@gmail.com

Attachment: See, below

April 3, 2020

APPLYING HHS'S GUIDANCE FOR STATES AND HEALTH CARE PROVIDERS ON AVOIDING DISABILITY-BASED DISCRIMINATION IN TREATMENT RATIONING

On March 28, 2020, the U.S. Department of Health and Human Services issued a Bulletin entitled "Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)," stating "HHS is committed to leaving no one behind during an emergency, and this guidance is designed to help health care providers meet that goal...Persons with disabilities...should not be put at the end of the line for health services during emergencies. Our civil rights laws protect the equal dignity of every human life from ruthless utilitarianism." The Bulletin offers broad guidance on the obligations of states and health care providers to comply with federal disability rights laws in developing treatment rationing plans and administering care in the event of a shortage of medical equipment, hospital beds, or health care personnel. This document from organizations with expertise in federal disability rights laws provides a more detailed explanation of how the requirements set forth in the HHS Bulletin would apply and how states and health care providers can take steps to modify policies and practices to avoid disability discrimination."
Guiding Principles for Avoiding Disability Discrimination in Treatment Rationing

- The lives of people with disabilities are equally worthy and valuable as those of people without disabilities.
- People with disabilities must have an equal opportunity to receive life-sustaining treatment.
- The fact that an individual with a disability requires support (minimal or extensive) to perform certain activities of daily living is not relevant to a medical analysis of whether that individual can respond to treatment.
- Doctors and triage teams must refrain from employing assumptions and stereotypes about the worth or quality of the life of a person with a disability in making decisions about medical treatment.
- Doctors and triage teams must not assume that they are free from conscious or unconscious bias in making critical life and death health care decisions, given the reality that people with disabilities have long experienced discrimination in receiving medical care.
- To avoid discrimination, doctors or triage teams must perform a thorough individualized review of each patient and not assume that any specific diagnosis is determinative of prognosis or near-term survival without an analysis of current and best available objective medical evidence and the individual's ability to respond to treatment.

- Doctors and triage teams must not reallocate ventilators of individuals with disabilities who use ventilators in their daily lives and come to the hospital with symptoms of COVID-19. Individuals with disabilities who use ventilators in their daily lives should be

allowed to continue to use this personal equipment if they receive COVID-19 treatment at a hospital.

- Federal disability rights laws—including the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act—broadly protect people with disabilities against discrimination in receiving medical treatment. These laws apply to hospitals experiencing a medical equipment, bed, or staffing shortage during the COVID-19 pandemic as well as state policies concerning how resources should be allocated in the event of such shortages.

Interpreting the HHS-OCR Bulletin

Excerpts from the Bulletin are provided in bold below with explanatory notes following.

“In this time of emergency, the laudable goal of providing care quickly and efficiently must be guided by the fundamental principles of fairness, equality, and compassion that animate our civil rights laws. This is particularly true with respect to the treatment of persons with disabilities during medical emergencies as they possess the same dignity and worth as everyone else.”

- Social characteristics, including but not limited to race, ethnicity, gender, national origin, sexual orientation, religious affiliation, and disability unrelated to near-term survival, should not be used as criteria in making resource or service allocation decisions during public health emergencies. These characteristics serve no meaningful purpose in differentiating between people in the context of allocation decisions. Moreover, categorization of people according to these types of characteristics is often used as pretext for discrimination and reduced access to medical care for marginalized groups. Therefore, use of social characteristics as allocation criteria is unacceptable.
- To ensure that these broad principles of non-discrimination, equal treatment, and respect for the value and dignity of people with disabilities are implemented, each plan addressing allocation of scarce resources during the COVID-19 pandemic (“plan”) should begin with:
 1. a non-discrimination clause that serves as a foundation to inform the decision making process that follows; and
 2. a reminder to physicians and triage teams of possible biases that could arise that must be negated.
- Any training of physicians or triage teams about how to allocate scarce resources in providing treatment during this epidemic should also include non-discrimination training.

- All plans that advise on allocation of medical resources during a shortage must be made publicly available and widely distributed to stakeholders, including hospital administrators, medical professionals, state and local disability organizations including the Protection & Advocacy network, chapters of The Arc, and Centers for Independent Living among others.
- Any plan must include an appeal process that is both explained and available to all patients.

“[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.”

- All persons should be eligible for, and qualified to receive, lifesaving care regardless of the presence of an underlying disability or co-morbid conditions, unless it is clear that the person will not survive in the immediate term or the treatment is contra-indicated.
- Treatment allocation decisions may not be made based on misguided assumptions that people with disabilities experience a lower quality of life or that their lives are not worth living. Such inaccurate assumptions continue to be pervasive in our society, and there is a widespread lack of understanding about how people with significant disabilities can have full, meaningful lives that others assume are off-limits to them.
- Every patient must be treated as an individual, not a diagnosis. This means that the mere fact that a patient may have a diagnosis of, for example, intellectual disability, autism, cystic fibrosis, diabetes, spina bifida, spinal muscular atrophy, or schizophrenia cannot be a basis (in part or whole) for denying care or making that person a lower priority to receive treatment.
- Generalized assumptions must be avoided and doctors must instead focus on the most current and best available objective medical evidence available to determine an individual patient’s ability to respond to treatment. Doctors must not assume that any specific diagnosis or disability automatically indicates a poor prognosis for near-term survival or an inability to respond to treatment: people with disabilities regularly outlive the prognoses doctors ascribe to them, often by decades. There must be a thorough, individualized review of each patient.
- Stereotypes and biases that devalue the lives of people with disabilities have no place in the decision-making process regarding whether to provide life-saving treatment. For example, value judgments about the fact that a patient may require extensive support in activities of daily living, uses augmentative or alternative communication, uses a

wheelchair, or experiences a psychiatric disability are irrelevant to decisions about whether such individuals should receive life-sustaining treatment.

- Protocols which equate survival with “health” or the absence of chronically debilitating symptoms, risk importing quality life criteria on the triage process.

“[G]overnment officials, health care providers, and covered entities should not overlook their obligations under federal civil rights laws to help ensure all segments of the community are served by: Providing effective communication with individuals who are deaf, hard of hearing, blind, have low vision, or have speech disabilities through the use of qualified interpreters, picture boards, and other means; Providing meaningful access to programs and information to individuals with limited English proficiency through the use of qualified interpreters and through other means; Making emergency messaging available in plain language and in languages prevalent in the affected area(s) and in multiple formats, such as audio, large print, and captioning, and ensuring that websites providing emergency-related information are accessible; Addressing the needs of individuals with disabilities, including individuals with mobility impairments, individuals who use assistive devices, auxiliary aids, or durable medical equipment, individuals with impaired sensory, manual, and speaking skills, and individuals with immunosuppressed conditions including HIV/AIDS in emergency planning; Respecting requests for religious accommodations in treatment and access to clergy or faith practices as practicable.”

- Treatment allocation decisions may not be made based on the stereotype that a person’s disability will require the use of greater treatment resources, either in the short or long term.
- Reasonable modifications must be made where needed by a person with a disability to have equal opportunity to benefit from the treatment. These include interpreter services or other modifications or additional services needed due to a disability. They also include permitting a person to continue using a ventilator for additional time where an underlying disability means that additional time is necessary for recovery.
- Assumptions should not be made about who is immunosuppressed, including individuals with HIV/AIDS, without an individualized review of each patient.
- Providing effective communication to individuals with disabilities who are patients or family members of patients is critical to ensuring compliance with federal law. Without effective communication, the patient’s autonomy and ability to participate in their care is taken away and doctors risk substituting misplaced assumptions and biases about the individual with a disability in place of verifiable information and medical history.
- Resources to help facilitate effective communication with patients and their family members with disabilities include:
 - U.S. Department of Justice: Communicating with People Who Are Deaf or Hard of Hearing in Hospital Settings

o U.S. Department of Justice: Access to Medical Care for People with Mobility Disabilities

o U.S. Department of Justice: Effective Communication Requirements

o Resources from Patient Provider Communication

o Resources from the National Association of the Deaf

o Resources from Communication First

- Providing effective communication to patients is critical and must not be overlooked during this pandemic. Without providing effective communication, it is impossible to avoid discrimination against patients with disabilities and/or their family members.

- If the individual requires an accommodation that involves the presence of a family member, personal care assistant, communicator, or similar disability service provider, knowledgeable about the management of their care and/or able to assist them with communicating their needs, to assist them during their hospitalization, this should be allowed provided that proper precautions can reasonably be taken to contain the spread of infection.

For more information, please contact:

Shira Wakschlag
The Arc of the United States
Shira@TheArc.org

Alison Barkoff
Cathy Costanzo
Center for Public Representation
abarkoff@cpr-us.org
ccostanzo@cpr-ma.org

Jennifer Mathis
Bazelon Center for Mental Health Law
jenniferm@bazelon.org

Samantha Crane
Autistic Self Advocacy Network
scrane@autisticadvocacy.org

Sam Bagenstos
sbagen@gmail.com

Claudia Center
Disability Rights Education & Defense Fund
ccenter@dredf.org

ENDORISING ORGANIZATIONS

Advocates for Youth
AIDS United
American Academy of Physical Medicine & Rehabilitation
American Association of People with Disabilities
American Association on Health and Disability

American Association on Intellectual and Developmental Disabilities
American Council of the Blind
American Kidney Fund
American Music Therapy Association
American Network of Community Options & Resources (ANCOR)
American Physical Therapy Association
American Psychological Association
American Therapeutic Recreation Association
APLA Health Association of University Centers on Disabilities (AUCD)
Autism Society of America
Autistic Self Advocacy Network
Bazelon Center for Mental Health Law
Black AIDS Institute
Brain Injury Association of America
Cancer and Careers
CancerCare
Center for Health Law and Policy Innovation
Center for Medicare Advocacy
Center for Public Representation
Christopher & Dana Reeve Foundation
Chronic Disease Coalition
Civil Rights Education and Enforcement Center
Collaboration to Promote Self-Determination
CommunicationFIRST
Community Options, Inc.
Council of Parent Attorneys and Advocates
Cure SMA
Disability Rights Advocates
Disability Rights Education and Defense Fund (DREDF)
Easterseals
Epilepsy Foundation
Family Voices
GLMA: Health Professionals Advancing LGBTQ
GO2 Foundation for Lung Cancer
HealthHIV
Hemophilia Federation of America
Hepatitis Education Project
Hyacinth AIDS Foundation
Immune Deficiency Foundation
International Myeloma Foundation
Justice in Aging
Lakeshore Foundation
Lambda Legal
LUNGevity Foundation
Mental Health America
Muscular Dystrophy Association

National Academy of Elder Law Attorneys
National Association of Councils on Developmental Disabilities
National Association of State Directors of Developmental Disabilities Services
National Association of State Head Injury Administrators
National Association of the Deaf
National Center for Learning Disabilities
National Center for Transgender Equality
National Coalition for MH Recovery
National Council on Independent Living
National Disability Rights Network
National Down Syndrome Congress
National Federation of the Blind
National Health Council
National Health Law Program
National Hemophilia Foundation
National Kidney Foundation
National Multiple Sclerosis Society
National Viral Hepatitis Roundtable
National Working Positive Coalition
Not Dead Yet
Paralyzed Veterans of America
Partnership for Inclusive Disaster Strategies
Prevention Access Campaign
Pulmonary Hypertension Association
RespectAbility
Self-Advocates Becoming Empowered (SABE)
Susan G. Komen
TASH, Inc.
The AIDS Institute
The Arc of the United States
The Center for HIV Law and Policy
The Coelho Center for Disability Law, Policy and Innovation
The Well Project
Treatment Action Group
United Spinal Association
US International Council on Disabilities