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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

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

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

- Resources from Patient Provider Communication
- Resources from the National Association of the Deaf
- 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.

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ENDORSING 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 Insitute
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
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