DISABILITY RIGHTS PENNSYLVANIA

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March 27, 2020

VIA ELECTRONIC MAIL

The Honorable Tom Wolf
Pennsylvania Office of the Governor
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govcorrespcrm@pa.gov

Dr. Rachel Levine, Secretary
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Secretary Teresa D. Miller
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Secretary Robert Torres
Pennsylvania Department of Aging
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aging@pa.gov

Re: *Assuring People with Disabilities Have Non-Discriminatory Access to Health Care for COVID-19 Treatment*

Dear Governor Wolf, Secretary Levine, Secretary Miller, and Secretary Torres:

On behalf of the undersigned groups, I am writing to express our deep concern that, in the event health care resources are insufficient to meet the need of COVID-19 patients and other patients, Pennsylvania hospitals and doctors will resort to rationing health care resources in a manner that discriminates against individuals with disabilities and violates federal non-discrimination laws. In fact, we understand that Pennsylvania has drafted a rationing policy based on the development of a crisis standard of care. Based on our limited knowledge of the policy, which has not been made public, we have serious concerns. It is imperative that you and your Administration work with the disability community in a transparent process to develop non-discriminatory statewide guidance and policies for health care providers if allocation of health care resources becomes necessary.

Potential Impact of COVID-19 on Health Care Resources and People with Disabilities

The current coronavirus pandemic will place heavy burdens on a health care system that appears ill-prepared to meet them. The need for medical resources in this crisis – including supplies, hospital beds, equipment such as life-saving ventilators, and services of health care professionals – may significantly exceed the availability of those resources.

Obviously, the optimal outcome would be to secure the needed resources to avoid the need for allocation of resources. But, if this is not possible, health care professionals may be forced to ration resources, withholding or withdrawing the care that many ill individuals will need to survive.

For people with disabilities, health care rationing will have particularly dire consequences. Individuals with certain disabilities, such as heart disease, pulmonary disease, weakened immune systems, and diabetes, are the most vulnerable to the harshest impact of COVID-19 and are most likely to need significant health care resources for a longer amount of time to combat the illness.

Aside from their greater need for more intensive health care during this crisis, people with disabilities are likely to be at higher risk for adverse consequences by the imposition of rationing due to biases of health care professionals. Studies have shown that health care professionals consistently undervalue and even devalue people with disabilities, assuming they have poor quality of life and have little value to society and thus subjecting them to discrimination when making treatment decisions. *See* National Council on Disability, *Medical Futility and Disability Bias* at 10 (Nov. 20, 2019), https://ncd.gov/sites/default/files/NCD_Medical_Futility_Report_508.pdf; Pauline W. Chen, M.D., "Disability and Discrimination at the Doctor's Office," *New York Times* (May 23, 2013), https://well.blogs.nytimes.com/2013/05/23/disability-and-discrimination-at-the-doctors-office/.

The potential need to allocate scarce health care resources as the pandemic expands, the more significant health care needs of many people with disabilities diagnosed with COVID-19, and the biases of medical professionals against many with disabilities is a recipe for disaster for the disability community. Without clear, non-discriminatory

standards for allocation of scarce resources by health care providers, people with disabilities will bear the brunt of this pandemic and face premature death.

Federal Non-Discrimination Laws

As you likely know, there are several federal laws that prohibit disability discrimination in the health care realm – Titles II and III of the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act (RA), and Section 1557 of the Patient Protection and Affordable Care Act (ACA). One of the core tenets of these laws is that decisions by covered entities must not be based on myths, stereotypes, and unfounded assumptions about people with disabilities; rather, they must be based on individualized determinations using objective evidence. *See School Bd. of Nassau County v. Arline*, 480 U.S. 273, 284-85, 287 (1987).

Title II of the ADA prohibits public entities (such as state and local governments) from excluding people with disabilities from their programs, services, or activities, denying them the benefits of those services, programs, or activities, or otherwise subjecting them to discrimination. 42 U.S.C. §§ 12131-12134. Implementing regulations promulgated by the United States Department of Justice (DOJ) define unlawful discrimination under Title II to include, *inter alia*: using eligibility criteria that screen out or tend to screen out individuals with disabilities, failing to make reasonable modifications to policies and practices necessary to avoid discrimination, and perpetuating or aiding discrimination by others. 28 C.F.R. §§ 35.130(b)(1)-(3), 35.130(b)(7)-(8).

Title III of the ADA imposes almost identical prohibitions on public accommodations, which includes hospitals and other health care providers. 42 U.S.C. §§ 12181(7)(F), 12182. Specifically, Title III bars health care providers from excluding people with disabilities from the full and equal enjoyment of their services and facilities. 42 U.S.C. § 12182(a). Congress construed this non-discrimination mandate broadly to bar, *inter alia*: use of eligibility criteria that screen out or tend to screen out people with disabilities; failure to make reasonable modifications to policies, practices, and procedures necessary to avoid discrimination; and aiding or perpetuating discrimination by others. 42 U.S.C. §§ 12182(b)(1)(D)(ii), 12182(b)(2)(i)-(ii); *accord* 28 C.F.R. §§ 36.204, 36.301, 36.302.

Section 504 of the RA similarly bans disability discrimination by recipients of federal financial assistance, including Pennsylvania agencies and most hospitals and health

care providers. 29 U.S.C. § 794(a). The breadth of Section 504's prohibition on disability discrimination is co-extensive with that of the ADA. *See Furgess v. Pennsylvania Dep't of Corrections*, 933 F.3d 285, 288 (3d Cir. 2019); *Berardelli v. Allied Services Institute of Rehabilitation Medicine*, 900 F.3d 104, 114-18 (3d Cir. 2018).

Finally, Section 1557 of the ACA provides that no health program or activity that receives federal funds may exclude from participation, deny the benefits of their programs, services or activities, or otherwise discriminate against a person protected by Section 504 of the RA. 42 U.S.C. § 18116; 45 C.F.R. §§ 92.101(a), 92.101(b)(2)(i). This includes an obligation to make reasonable modifications in policies, practices, and procedures necessary to avoid discrimination. 45 C.F.R. § 92.205.

Significantly, DOJ has explicitly instructed that Title II of the ADA applies to emergency preparedness efforts of state and local governments, writing:

> One of the primary responsibilities of state and local governments is to protect residents and visitors from harm, including assistance in preparing for, responding to, and recovering from emergencies and disasters. State and local governments must comply with Title II of the ADA in the emergency- and disaster-related programs, services, and activities they provide.

DOJ, *Emergency Management Under Title II of the Americans with Disabilities Act* at 1 (July 26, 2007), https://www.ada.gov/pcatoolkit/chap7emergencymgmt.htm. This policy makes plain that federal non-discrimination laws are applicable to emergency situations, such as the coronavirus pandemic.

Discriminatory Health Care Rationing

If health care resources must be rationed, it is ethically imperative and legally mandated that the rationing be conducted in a manner that does not discriminate against people with disabilities. Some rationing criteria or policies would almost certainly run afoul of federal anti-discrimination laws, including, for instance:

- Categorical exclusions from care based on illness, diagnosis, or pre-existing conditions – Eligibility standards that are facially discriminatory and

bar access to care based on specific illnesses, diagnoses, or conditions would not withstand scrutiny under federal law.

- Limits on access to health care based on quality of life considerations -- Quality of life considerations are not neutral, even when couched in seemingly neutral or objective language or terms. Such considerations are driven by prejudices and stereotypes and, as applied, will subjectively devalue the lives of people with disabilities. The use of such criteria to allocate health care will inevitably lead to denial of care based on disability in violation of federal law.
- Exclusions based on likely need for duration of care – It is possible that people with disabilities whose health has already been compromised may require more health care for a longer time to effectively treat COVID-19 than others without underlying disabilities. While this might appear to be an acceptable standard to maximize the use of resources, it still raises significant concerns about discrimination. First, it disregards the obligation to accommodate people with disabilities. If the individuals with disabilities could benefit from, for example, ventilator treatment, but merely require more time for the treatment to be effective, then an extension of time for treatment is an appropriate accommodation to assure that they have meaningful access to the service, as required by federal anti-discrimination laws. Second, the determination about the projected length of care needed is subjective and raises the possibility that biases will lead to denials of care based on disability.

At least two complaints have been filed with the United States Department of Health and Human Services' Office of Civil Rights (OCR). One challenges the State of Washington's plan to ration health care in response to a scarcity of resources caused by COVID-19. *Complaint of Disability Rights Washington, et al. against Washington State Dep't of Health, et al.* (Mar. 23, 2020), https://www.centerforpublicrep.org/wp-content/uploads/2020/03/OCR-Complaint_3-23-20-final.pdf. The complaint alleges that the Washington plan appears to give priority "to treating people who are younger and healthier and leaves those who are older and sicker—people with disabilities—to die" in violation of federal statutes barring disability discrimination. The second complaint challenges Alabama's plan to ration ventilators, which explicitly excludes people with intellectual disabilities from access to ventilators. *Complaint of the Alabama Disabilities Advocacy Program, et al.* (Mar. 24, 2020),

http://www.bazelon.org/wp-content/uploads/2020/03/3-24-20-AL-OCR-Complaint.docx.pdf.

In addition, the National Council on Disability (NCD) wrote to OCR about the impact of potential health care rationing during this crisis on people with disabilities, concluding:

> NCD strongly urges OCR to immediately issue a notice to the nation's medical providers of their obligations for non-discriminatory medical care under the ADA, the Rehabilitation Act, and the Affordable Care Act. The notice should include a statement on the historic and deep-seated biases and stereotypes about people with disabilities that have resulted in eugenics and lack of life-saving care, ask physicians to be mindful of this when making medical treatment decisions, and make clear that, even in an environment where health care resources are limited, the civil rights of people with disabilities cannot be suspended or limited.

National Council on Disability, *COVID-19 Letter to HHS OCR* (Mar. 18, 2020), https://www.ncd.gov/publications/2020/ncd-covid-19-letter-hhs-ocr.

Pennsylvania's Opportunity

While the draft policy has not been made public, it was reported in the Philadelphia Inquirer yesterday that Pennsylvania doctors will be making decisions about how to allocate resources based on a "combination of how critically ill a patient is and determining how long and whether they would benefit from ventilator treatment and prognosis over the short, medium, and long term." Jason Laughlin and Wendy Ruderman, "Who Lives, Who Dies: Pa., N.J. Facing Tough Priorities as COVID-19 Cases Mount," *The Philadelphia Inquirer* (March 26, 2020).

It is impossible for us to give adequate input on a policy we have not reviewed, but several aspects of this description raise grave concerns. First, while it is unclear how the proposed crisis standard of care will guide decision-making as to degree of illness, very critically ill patients are likely to be disproportionately individuals with pre-existing disabilities. Second, it appears how long a person would need a ventilator would be considered, which, as set forth above, is a discriminatory factor based on need for

duration of care. Third, the reference to a patient's prognosis over time signals quality of life considerations, which, as set forth above, are illegal.

Another troubling detail from the article: Dr. Levine's comments suggest that physicians and health systems would be guided to provide health care without following the crisis standard of care, but instead by "exercise[ing] their judgment." This is improper, particularly when that unlawfully discriminates against people with disabilities.

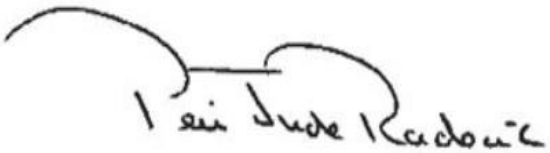
These times require strong leadership from Pennsylvania. We need clear, non-discriminatory statewide mandatory policies and guidance. Absent this, individual hospitals and health care professionals are in danger of making decisions that will result in the rationing of resources in a discriminatory manner. These decisions have consequences that are not reversible and could lead to unnecessary deaths of people with disabilities.

We call on your Administration to take the lead and convene stakeholders as soon as possible and, using an open and transparent process, develop non-discriminatory standards to be used by hospitals and health care providers in the event health care rationing is needed. The first step is to immediately provide a copy of the draft document to us for review and comment.

Time is of the essence and we are prepared to work with your Administration to address this life-and-death issue.

Thank you for your prompt consideration of this urgent request.

Respectfully,



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On behalf of:

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Arc of Greater Pittsburgh
The Arc of Pennsylvania
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Center for Independent Living of Central PA
Center for Independent Living of North Central PA
Community Healthcare Advocacy Team for Individuals with Disabilities (CHATID)
Community Legal Services of Philadelphia
Disability Empowerment Center
Disabled In Action of PA
FISA Foundation
GDC Lifespan, Inc.
Institute on Disabilities, Temple University

Leahy Life Plan
Liberty Resources
Life and Independence for Today (LIFT)
Little Lobbyists Pennsylvania
NAMI Keystone PA
North Central PA ADAPT
Northeast Pennsylvania Center for Independent Living
PA ADAPT
PA Families Need Nurses Now
PA Waiting List Campaign
Partnership for Inclusive Disaster Strategies
PASILC
Pennsylvania Assistive Technology Foundation
Pennsylvania Council on Independent Living
Pennsylvania Family Network
Pennsylvania Health Access Network
Pennsylvania Health Law Project
Philly ADAPT
Roads to Freedom
Self Advocates United as 1
SeniorLAW Center
Speaking for Ourselves
Vision for Equality

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