Disability, Access, and Other Considerations: A Title II Framework for a Pandemic Crisis Response (COVID-19)

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DISABILITY, ACCESS, AND OTHER CONSIDERATIONS:
A TITLE II FRAMEWORK FOR A PANDEMIC CRISIS RESPONSE
(COVID-19)

GEORGE M. POWERS,* LEX FRIEDEN** & VINH NGUYEN***

ABSTRACT

This Article examines how plans for emergency medical rationing during the COVID-19 pandemic may discriminate against those with disabilities. More specifically, this Article lays out the obligation of state and local governments under Title II of the ADA in creating and enforcing equitable and fair rationing plans during this COVID-19 crisis. For example, ventilator shortages are a common occurrence. The ADA, similar to other civil rights laws, operates so that a person with a disability is not denied a ventilator or other resources because of his/her disability. One reason that a person with a disability may be denied limited medical resources is because of the biases a medical professional may have. They may view the life of a person with a disability as less valuable than someone that does not have a disability. The decision may also be swayed by assumptions about a person’s immune system or other medical conditions.

Title II of the ADA governs state and local governments. Its application is very broad. State governments already have obligations to create emergency preparedness plans that serve those with disabilities. This obligation extends to the rationing of scarce medical resources during the COVID-19 pandemic. The traditional relationship between the state and the practice of medicine is one of many considerations that also point to this obligation.

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I. INTRODUCTION

A pandemic like COVID-19 creates situations where the needs of the patient population overwhelm the medical resources available. The United States (U.S.) government, like the governments of many other countries, has not been able to weather the challenge. Life and death decisions have had to be made because there were not enough ventilators to treat everyone. These situations raise a number of ethical, moral, and legal questions, answers to which have been unneeded for a century. For example, if three patients with the novel coronavirus need a ventilator to survive, and if there are only two ventilators available at a hospital, then who decides which two patients get a ventilator? How is that decision influenced if one of those patients has a disability?

A number of difficult decisions have had to be made during emergencies, and planning for these scenarios is a responsibility of health care providers and the government. This Article will explore how to create a “pandemic crisis response plan” that is consistent with Title II of the Americans with Disabilities Act (ADA).

COVID-19, and its impact on the global population, is unlike any crisis in modern history. Almost every nation is dealing with this virus. There are a number of social and economic consequences of this virus, and the most


5. Title II applies to state and local governments, and guarantees full and equal access to their services, programs, or activities. ADA Title II, Public Services, 42 U.S.C. § 12132.

6. COVID-19 is the infectious disease caused by the most recently discovered coronavirus. This new virus and disease were unknown before the outbreak began in Wuhan, China, in December 2019. Coronavirus Disease (COVID-19), WORLD HEALTH Org. (Apr. 15, 2020), https://www.who.int/news-room/q-a-detail/q-a-coronaviruses.


devastating may be the real cost of human life. Very few are lucky enough to not feel the direct impact of the medical emergencies created by the novel coronavirus. Essential and frontline workers face especially great risks.

II. BACKGROUND

During pandemics, health care providers and government officials may have to decide how to allocate a limited amount of medical resources to a population that cannot be wholly served. Unfortunately, “state officials and hospitals are quietly preparing to make excruciating decisions about how they would ration lifesaving care.”10 Many states,11 and countless health systems, are putting in place “policies to determine which coronavirus patients would get ventilators if they run short — essentially deciding whose lives to save first.”12 These horrific choices have had to be made both internationally13 and in the United States.14 Moreover, COVID-19 may cause other shortages of medical resources and equipment.15

People with disabilities are generally perceived to have increased susceptibility to other health problems and underlying conditions that may require health care providers to use more effort, time, space, and scarce medical resources for treatment.16 These perceptions are reinforced by how most health

13. Ferraresi, supra note 1 (discussing full intensive care units and ventilator rationing in Italy).
16. See Disability and Health Care Information for Health Care Providers, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/ncbddd/disabilityandhealth/hcp.html (last updated Sept. 15, 2020) (highlighting guidance for health care providers to allocate more time
care providers perceive people with disabilities in the first place. In short, doctors, nurses, and other health care providers operate under the “medical model” of disability. 17 By virtue of their education, training, and experience, most health care professionals have deep-rooted perceptions that the quality of life for a person with a disability is lower than that of a person without a disability. 18 The medical model produces an unhealthy view of disability as something that needs fixing, 19 as opposed to a characteristic that is a part of a person’s identity. 20

Many people with disabilities have previously experienced subpar and discriminatory treatment from health care providers, 21 but discriminatory treatment in the midst of a pandemic can result in death. All of these factors, in addition to the pressures of a crisis, can create a discriminatory environment in which people with disabilities are denied care in favor of the welfare of those without disabilities.

Our Constitution, civil rights laws, and shared values do not support a purely utilitarian approach to any situation, much less a crisis. 22 On the other hand, there are forces in every society that drive utilitarian values. For example, a number of international governments are suppressing data, information, and the press to propagandize the true impact of COVID-19. 23 A healthy economy is an important factor that governments need to legitimately stay in power. 24

and communication efforts to disabled people, who are susceptible to health problems and secondary conditions).

17. Simon Brisenden, Independent Living and the Medical Model of Disability, DISABILITY, HANDICAP & SOC’Y 173, 176 (1986) (describing how medical professionals tend to view disabilities as issues requiring treatment without considering an individual’s goals for his/her quality of life).

18. See id. at 177 (explaining how it is inappropriate to view a disabled person as “suffering” from a disease, because that emphasizes physical limitations and low quality of life expectations).

19. Pun intended.

20. Brisenden, supra note 17, at 173.


Furthermore, there are economic forces to which health care systems will bend. In the United States, at least, the organization of nearly all health care providers parallels that of other businesses. These entities have economic incentives to underreport their failures and maximize their successes. On a more micro level, health care professionals are under too many psychological burdens and professional demands to make speedy decisions about the fair administration of limited resources. Without the proper application of our civil rights laws, other rules, and norms, we risk loss of control of the immediate COVID-19 crisis and much more for the future.

The Office for Civil Rights (OCR) within the U.S. Department of Health and Human Services released a bulletin that summarized the protections provided by our civil rights laws. Roger Severino, the Director of OCR, said, “Persons with disabilities, with limited English skills, or needing religious accommodations should not be put at the end of the line for health services during emergencies.” His statement signifies the necessity of enforcing our civil rights laws during this pandemic.

People with disabilities, like other marginalized groups, have legitimate concerns and fears about not receiving equitable health care during the COVID-19 pandemic. History and past experiences have given form to these fears, and they can become a reality without proper safeguards.

The unfortunate story of one patient in particular exemplifies the resulting cruelty of this perfect storm. Mr. Michael Hickson was a middle-aged father of five with quadriplegia, a brain injury, and vision loss. Mr. Hickson initially became disabled in 2017 after he went into sudden cardiac arrest. His assigned legal guardian due to the accident that caused his disability, and


28. OFF. FOR C.R., supra note 22.

29. Id.


31. Id.


33. Id.
after his wife objected to his institutionalization in a nursing facility. Mrs. Hickson instead wished for rehabilitative services for her husband. Tragically, Mr. Hickson became ill at his assigned nursing facility with the SARS-CoV-2 virus, which causes COVID-19, and was taken to the hospital’s intensive care unit (ICU). Against his wife’s wishes, who was not his legal guardian, Michael Hickson was denied medical treatment. Mrs. Hickson recorded a conversation with the treating doctor in which the doctor stated that medical care would be withheld because of Mr. Hickson’s “quality of life.”

The decision not to treat was ultimately made by Mr. Hickson’s legal guardian, the medical professionals, and the probate court. The hospital later argued that ventilating Mr. Hickson would have been futile and that it was making the “humane” decision by denying care. Mr. Hickson’s sister, a fellow at George Washington University Hospital, agreed with the decision to withhold intubation and other medical care. His sister’s opinion at least demonstrates how influential the medical model can be for providing care to a person with a disability. Two of his closest family members reached polar opposite conclusions about his lifesaving medical care.

Any perspective on the decision to withhold medical treatment has moral implications that go far beyond the scope of this Article. In relation to disability rights however, it is very significant that Mr. Hickson’s “quality of life” was a factor in the treating doctor’s decision. The conversation was recorded by Mrs. Hickson, even though the hospital officials later clarified that they withheld treatment because Mr. Hickson would not survive it.

The inconsistency and controversy inherent in Mr. Hickson’s story can be partially illuminated by the medical model’s influence on the medical professionals that made the ultimate decision. This bias can apply to Mr. Hickson’s sister as well. The medical professionals ultimately believed that they had the authority to make a decision about how a person’s disability impacted that person’s quality of life. As a person with a disability, I have no doubt that

34. Id.
35. Id.
36. Id.
37. One Man’s COVID-19 Death, supra note 32.
39. Id.
40. One Man’s COVID-19 Death, supra note 32.
42. Id.
43. Id.
44. One Man’s COVID-19 Death, supra note 32.
my disability affects my quality of life.45 That impact, however, is very complex and should not be a consideration in whether or not I receive lifesaving medical treatment.46 The expectation is that those kinds of medical decisions are based on objective medical evidence.47 How a person’s disability impacts his or her quality of life is far too personal, subjective, and complicated to be made by medical professionals, especially when those professionals are under the pressures of emergency situations.48 It is all of the three authors’ opinion that the very nature of how a disability impacts a person’s quality of life precludes it from a medical professional’s consideration. Even though it may not be apparent, these kinds of considerations violate civil rights laws like the ADA.

III. THE AMERICANS WITH DISABILITIES ACT

The overarching purpose of the ADA is to stop discrimination against people with disabilities.49 The ADA protects people on the basis of disability in the same way that the Civil Rights Act of 1964 protects people on the basis of race, color, religion, sex, or national origin.50

There are five Titles under the ADA. Title I applies to employment; Title II applies to “programs and services” of state and local governments; and Title III applies to places of public accommodation.51 Title IV and V provide basic telecommunications requirements and miscellaneous provisions, respectively.52

Title II mandates that people with disabilities not be denied access to the “services, programs, or activities of a public entity.”53 The term “services, programs, or activities” is intended to be interpreted broadly and to apply to virtually anything that a state or local government does.54 Emergency management,55 planning, and preparedness are obviously services, programs, or

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45. Personal opinion of author, George Powers.
47. Id. at 139.
48. The decision to withhold medical care was not based on a shortage of medical supplies.
One Man’s COVID-19 Death, supra note 32.
51. 29 C.F.R. § 1630.2(b) (2011); 42 U.S.C. §§ 12131(1)(A), 12132, 12181(7).
54. See, e.g., Armstrong v. Wilson, 124 F.3d 1019, 1023 (9th Cir. 1997); Yeskey v. Pa. Dep’t Corrs., 118 F.3d 168, 171 (3d Cir. 1997).
activities meant to be included under Title II. Therefore, these “programs and services” must be accessible to people with disabilities. Public entities are also generally prohibited from applying “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.”

The only exception to this requirement is if a public entity can show that discriminatory criteria are necessary for the program or service. State governments have a distinctive responsibility to plan for the non-discriminatory allocation of medical resources during a pandemic crisis as it relates to people with disabilities. Health care providers need to have a consistent and reliable standard to apply during medical emergencies like the one created by COVID-19. They are under intense distress and may not appreciate all the considerations. A uniform standard or guideline eliminates the need to make such critical decisions under duress and on the spot. One must also consider the relationship that state governments have to health care systems and providers. States license and oversee medical professionals to guarantee that certain standards are met.


58. Id. §§ 35.130(b)(1)(iv), (b)(8). Examples of programs and services include public parks and swimming pools, city hall meetings, emergency response services, and public sidewalks.


61. Tait Shanafelt et al., Understanding and Addressing Sources of Anxiety Among Health Care Professionals During the COVID-19 Pandemic, 321 JAMA 2133, 2134 (2020).


63. “State medical boards are the agencies that license medical doctors, investigate complaints, discipline physicians who violate the medical practice act, and refer physicians for evaluation and rehabilitation when appropriate. The overriding mission of medical boards is to serve the public by protecting it from incompetent, unprofessional, and improperly trained physicians. Medical boards accomplish this by striving to ensure that only qualified physicians are licensed to practice medicine and that those physicians provide their patients with a high standard of care.

The right to practice medicine is a privilege granted by the state. Each state has laws and regulations that govern the practice of medicine and specify the responsibilities of the medical board in regulating that practice. These regulations are laid out in a state statute, usually called a medical practice act. State medical boards establish the standards for the profession through their
program—the state medical board—that falls under the umbrella of Title II.64 Because the right to practice medicine is so strongly regulated by the state, there is an obligation to plan specifically for medical equipment rationing during a pandemic.

IV. OTHER LAWS

Plan developers also have to consider other laws, in addition to the ADA. For example, emergency plans have to be consistent with due process standards.65 Section 1557 of the Patient Protection and Affordable Care Act66 also prohibits discrimination on the basis of race, color, national origin, sex, age, or disability in the provision of health care.67 The Public Readiness and Emergency Preparedness (PREP) Act68 and other laws also need to be considered.

Section 504 of the Rehabilitation Act of 1973 contains protections for those with disabilities that are similar to the ADA.69 Many health care providers are private entities that are covered by Title III of the ADA.70 Section 504, Title II, and Title III essentially have the same protections for individuals with disabilities, but each applies to different entities.71 Fortunately, nearly all health care providers are covered by at least one of these three laws.72

interpretation and enforcement of this act.” Drew Carlson & James N. Thompson, The Role of State Medical Boards, 7 AMA J. ETHICS 311, 311 (2005).


67. Id.


71. Id.

Part focuses on a state government’s obligation under Title II, but the framework can be applied to private entities as well.

V. COMPLAINTS

Currently, a majority of states have plans for the allocation of ventilators and other medical resources.73 Most of these plans have standards that endorse rationing medical care based on disability; in other words, medical professionals are instructed to exclude individuals with disabilities.74 Recently, Disability Rights Washington and other advocacy groups opposed Washington State’s “rationing scheme.”75 Washington’s plan is reported to “assess factors such as age, health, and likelihood of survival in determining who will get access to full care and who will merely be provided comfort care, with the expectation that they will die.”76 Washington’s Department of Health also urged triage teams to consider “transferring hospital patients with ‘loss of reserves in energy, physical ability, cognition and general health’ to outpatient or palliative care.”77

The Center for Public Integrity conducted a study that examined the policies and guidelines from a number of states for the rationing of ventilators and medical resources during a pandemic crisis.78 The study found that fourteen states promote or require standards that discriminate against those with disabilities. For example, “Alabama, Louisiana, Pennsylvania, Texas and Utah direct hospitals to take dementia into account” in deciding who receives a ventilator.79 A number of disability rights advocacy groups have filed complaints and lawsuits in other states.80

VI. TITLE II FRAMEWORK FOR PANDEMIC CRISIS RESPONSE

Cases like Mr. Hickson’s illustrate the need for proper Title II considerations and guidelines.81 Doctors and health care professionals have strong tendencies

74. Id.
76. Id.
77. Id.
78. Whyte, supra note 73.
79. Id.
to discriminate, usually unknowingly, because the medical model is so engrained in their daily operations.82

In adopting a plan for the allocation of ventilators and other medical resources, public entities must be consistent with Title II. There are a number of access and discrimination considerations. Essentially, those who draft standards for medical equipment rationing have to ask the following questions about every element of the plan:

i. Does this standard exclude an individual from receiving the necessary medical care based on a determination about that individual’s disability that is “unrelated to near-term survival”?83
   a. Decisions about “near-term” survival must be based on individualized and objective medical evidence.84 This is an essential safeguard of any plan as the medical field is inherently biased against people with disabilities.85
   b. Decisions cannot be based on assumptions. Some common assumptions, meant to be illustrative and not exhaustive, are:
      • A person with a disability requires the use of more medical resources. Health care professionals cannot base their decisions on the assumption that a person with a disability will need more medical resources during and after recovery.86
      • A person who has a disability has a lower quality of life.87
      • A person with a disability has a lower chance of survival because of a weakened immune system.88
   c. Are there safeguards or chances for review when a health care provider makes a decision about the medical care of a person with a disability?

82. Stephen Bunbury, Unconscious Bias and the Medical Model: How the Social Model May Hold the Key to Transformative Thinking About Disability Discrimination, 19 INT’L. J. DISCRIMINATION & L. 26, 28 (2019).
84. Id.
86. DISABILITY RTS. EDUC. & DEF. FUND, supra note 83.
87. Id.
88. Id. This assumption is usually made about those with HIV/AIDS, but it can also be made about those who have other disabilities.
During the COVID-19 crisis, family members have limited access to patients in hospitals. COVID-19 patients are isolated to reduce the chance the disease will transfer. “The isolation extends beyond coronavirus patients.” Proper oversight and input from family members is required.

ii. Does this standard confiscate medical equipment away from a person with a disability that uses that medical equipment as a part of his/her daily life?
   a. Are medical resources being taken away from a person that ordinarily uses those resources?
   b. Health care providers 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.

Public entities may try to apply a direct threat exception to these standards to deny health care to individuals with disabilities. Title II “does not require a public entity to permit an individual to participate in or benefit from the services, programs, or activities of that public entity when that individual poses a direct threat to the health or safety of others.” These assessments must be made on an individual basis and based on objective evidence. Circumstances may align in a way that a person’s disability creates a unique risk to the health of others. Even then, health care professionals have to find a way to address the risk, and they cannot simply deny care or services to the person with disabilities. The “direct threat” standard is a very high and difficult threshold to meet. Any decision to exclude someone because of a direct threat determination ought to be made by a group of high-level officials. During the COVID-19 crisis, there is

91. DISABILITY RTS. EDUC. & DEF. FUND, supra note 83.
92. 28 C.F.R. § 35.139(a) (2020).
93. Id. § 35.139(b).
a shortage of personal protective equipment (PPE). A direct threat claim cannot be based on the shortage of PPE equipment, since the risk created is not a result of a person’s disability. In other words, a direct threat claim must be based on a characteristic of a person’s disability.

These considerations promote consistency with Title II. Seeking the input of disability-associated groups in the community can be beneficial. These are, after all, the people to be served in an emergency. Interacting with the community can be very useful since disability is such a wide-ranging characteristic. These deep systemic biases in the medical community can also be remedied by regular trainings and by employing those with disabilities as medical professionals.

VII. CONCLUSION

It is a bizarre reality in which we find ourselves now. There are many uncertainties, fears, and anxieties that are looming as we face this pandemic. History has taught us that crises create environments where repressive governments rise. The worse the emergency, the worse the government and the atrocities it can commit. We have to remember that civil rights laws are one of the many institutional protections we have in place to prevent the rise of such oppressive governments, and disregarding or ignoring these laws during emergencies only fosters the harmful ingredients necessary for such regimes. Ingredients such as high poverty and unemployment rates, victimization or perceived victimization of minority populations, and the distortion of truth can increase the influence of repressive regimes. The denial of health care based on disability is a small and complex ingredient, making its occurrence more likely.

Those with disabilities experience disparities in receiving equitable health care generally. Emergencies, like the COVID-19 pandemic, amplify these disparities, and create scenarios where discriminatory decisions can thrive.

Finally, the ADA is just one civil rights law. It is the authors’ intent that this Article be used to understand the duty that state governments owe to individuals


with disabilities during an emergency situation like a pandemic. The state’s traditional role of overseeing medical practice, the inadequacy of other decision makers, the need for uniformity, the inherent discriminatory nature of the medical field, and a number of other reasons point to the state’s duty to create an inclusive pandemic crisis response plan. In planning for how to allocate limited resources during such emergencies, the principals of the ADA must be observed. Rationing plans cannot have elements where assumptions, biases, and misinformation are part of the equation.