

AFTERWORD: THE ADA’S IMAGINED FUTURE

Doron Dorfman†

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INTRODUCTION

In a seminal text in disability studies, Alison Kafer addresses the concept of futurity—an investment in and attention to the future.¹ Specifically, Kafer confronts a common notion, namely that no conceptualization of a good future, neither on the individual nor on the public level, can include disabled bodies/minds. A future involving disability is too often deemed to be banal, pathetic, and lonely. It is also costly and futile to society as a whole that allegedly receives nothing in return from people with disabilities. That is why conceptions of the future typically include methods to normalize and eliminate disability through means of coercive treatments or selective abortion.² Yet Kafer tells of a different “imagined future,” one that is ripe with community and possibility. It includes finding supportive relationships, having a family, and embarking on a fulfilling career.³ And it is a future filled with activism, meaningful work for social justice, and coalition building with

† Associate Professor, Syracuse University College of Law. JSD, Stanford Law School. I would like to thank Yaron Covo, Liz Emens, Slava Greenberg, Arlene Kanter, Kat Macfarlane, Jamelia Morgan, Blake Reid, and Heather Rothman for their extremely helpful feedback and to Nikkia Knudsen and Hilda Frimpong for their excellent editing work. I dedicate this piece to the memory of Stacey Park Milbern, a fierce disability justice advocate who passed away in May 2020 at the age of 33. Stacey has left an uncanny legacy of leadership, strength, and compassion way beyond her years. I feel fortunate to have met her while living in the Bay Area and have her talk with the students in my disability studies class, an unforgettable meeting for all of us. May her memory be a revolution.

1. ALISON KAFER, FEMINIST QUEER CRIP 28 (2013).

2. As Kafer reminds us “Disability activists have long railed against a politics of endless deferral that pours economic and cultural resources into “curing” future disabled people (by preventing them from ever coming into existence) while ignoring the needs and experiences of disabled people in the present.” *Id.* at 29.

3. *See generally id.* at 2 (explaining an imagined future for persons with disabilities).

other movements to benefit the masses.⁴ Kafer concludes, “I have written this book because I desire *crip*⁵ futures: futures that embrace disabled people, futures that imagine disability differently, futures that support multiple ways of being.”⁶

While this Special Volume reflects on the first three decades of the Americans with Disabilities Act (ADA), this essay, similar to Kafer’s work, delineates an imagined future for the ADA, one that would create the infrastructure allowing people with disabilities to thrive and have a meaningful and rich future such as what Kafer imagines.

Many issues can spring to mind when discussing a brighter future for disability justice, from better integration in the workforce to the creation of support structures for disabled parents. Due to limited space, however, I will focus on three primary reforms to the ADA that reach well beyond this legislation as we know it today. The first is the need to have a specific chapter and regulations on emergency relief for people with disabilities. As disability law scholars⁷ including most recently Ani

4. See generally *id.* at 150–51 (imagining what accessible futures might look like, focusing on activism, social justice, and coalition building).

5. The negatively charged term “crip” (short for “cripple”) was reclaimed by many in the disability community who use it in a positive manner to denote their own agency over previously subaltern identifiers. See SIMI LINTON, CLAIMING DISABILITY: KNOWLEDGE AND IDENTITY 11 (1998). This cultural move led to theoretical-critical strand within disability studies known as crip theory that joins the ranks of critical race theory, queer theory, and critical feminist studies. See Rabia Belt & Doron Dorfman, *Disability, Law, and the Humanities: The Rise of Disability Legal Studies*, in OXFORD HANDBOOK OF L. & HUMAN. 145, 150 (Simon Stern, Maksymilian Del Mar & Bernadette Meyler eds., 2020).

6. KAFER, *supra* note 1, at 45.

7. Adrien A. Weibgen, *The Right To Be Rescued: Disability Justice in an Age of Disaster*, 124 YALE L.J. 2406, 2410 (2015) (stating: “As this nation’s experiences during Hurricane Katrina, Hurricane Sandy, and other disasters have made clear, extreme weather events and other emergencies do not impact all populations equally”); Jasmine E. Harris, *The Frailty of Disability Rights*, 169 UNIV. PA. L. REV. ONLINE 30, 42, 63 (2020) (“While the current pandemic is unprecedented in scope, the United States has experienced natural disasters and other national emergencies that previously raised questions about the requirements and capacity to serve students with disabilities”; “From gun control to immigration and natural disasters such as wildfires and hurricanes, disability rights matter to our national security risk assessment, planning, and responses”); Rabia Belt & Sharon Driscoll, *After the Hurricane: Rabia Belt on Challenges Facing People with Disabilities in Disasters*, STANFORD LAW BLOG (Sep. 7, 2017), <https://law.stanford.edu/2017/09/07/after-the-hurricane-rabia-belt-on-challenges-facing-disabled-in-disasters/> (“Natural disasters are difficult for everyone, but they are a particular challenge for people with disabilities. Emergency preparedness plans may not address the problems that people with disabilities face”); Jessica Roberts, *An Area of Refuge: Due Process Analysis and Emergency Evacuation for People with Disabilities*, 13 VA. J. SOC. POL’Y & L. 127 (2005) (“In discussing emergencies, everyone knows the phrase ‘Women and children first.’ While this notion seems antiquated, there is still a hierarchy of rescue that has nothing to do with age or gender. This platitude might read, ‘People with disabilities last’”).

Satz in a forthcoming article discuss,⁸ if the recent years have taught us anything, it is that people with disabilities are often left behind during natural disasters or in a global health crisis. And though the ADA may apply in retrospect through litigation, guidelines for creating emergency plans that would help save lives of disability communities *ex ante* should be imbedded in legislation. The second reform relates to the enforcement of accessibility standards in both the built and online environments. In response to the ADA accessibility standards' failure to be widely and properly enforced, I suggest a move to a centralized system alongside the current model of private enforcement to ensure greater compliance with these standards. The third, and perhaps most ambitious reform, recognizes the need to ensure universal health-care coverage. I join other disability law scholars to suggest that to truly remove structural barriers and allow inclusion of disabled individuals in all areas of life, we need to eliminate health disparities between disabled and nondisabled Americans. Doing so means guaranteeing meaningful access and coverage of services even beyond that which is provided in the Affordable Care Act.

Such a broad view for the imagined future of the ADA recognizes the limitation of one antidiscrimination statute and moreover aligns with the disability justice framework. Disability justice is often referred to as the "second wave" of the disability rights movement. This approach seeks to transform social conditions and norms to eradicate ableism and to ensure equality in a broad sense.⁹ The ambitious goals I set for the future can only be achieved through an expansion of the current scope of the antidiscrimination mandate underlining the ADA as it exists today.¹⁰

I. DISASTER RELIEF AND PROTECTION

As natural disasters and global health crises occurring throughout the first decades of the twenty-first century have demonstrated, emergencies do not strike all populations equally.¹¹ Time and time again, people with disabilities have been disproportionately affected by those emergencies, often left to die when nondisabled people are saved.

8. Ani Satz, *Principals and Pandemics: Overcoming Structural Disability Discrimination During Public Health Emergencies* (unpublished manuscript, forthcoming).

9. See SINS INVALID, SKIN, TOOTH AND BONE: THE BASIS OF MOVEMENT IS OUR PEOPLE 16, (2d ed. 2019); LEAH L. PIEPZNA-SAMARASINHA, CARE WORK: DREAMING DISABILITY JUSTICE 11 (2018); Natalie Chin, *Centering Disability Justice*, 71 SYRACUSE L. REV. 684 (2021).

10. For a discussion of the limitation of the current antidiscrimination model of the ADA see *infra* notes 95–103 and accompanying text.

11. Weibgen, *supra* note 7, at 2410.

For example, the National Council on Disability reported that during Hurricane Katrina, which hit New Orleans in 2005, the American Red Cross implemented a policy that refused shelter access to people with obvious disabilities.¹² There was also no accessible transportation to help people with disabilities evacuated from their homes reach medical facilities.¹³ As a consequence, a disproportionate number of fatalities in New Orleans consisted of people with disabilities.¹⁴ The story of Ethel Freeman—a ninety-one-year-old Black woman and wheelchair user who evacuated from her flooded house, arrived to an overwhelmed shelter from which she was turned away, and who eventually died waiting for a bus that never came to carry her to safety—has become “a symbol of government failure.”¹⁵ Nevertheless, the wrongful death claim filed by Freeman’s son against the municipal authorities was dismissed under Louisiana’s sovereign immunity statute.¹⁶

Then there was the killing of four Black patients with disabilities by medical staff at the Memorial Medical Center that was hit hard by Hurricane Katrina.¹⁷ Prior to a delayed evacuation, in a flooded facility with no electricity or air conditioning, a doctor and two nurses decided to inject Emmett Everett, Sr. (age sixty-one), Hoffis Alford (age sixty-six), Ireatha Watson (age eighty-nine), and Rose Savoie (age ninety-one) high doses of pain medication that caused their deaths.¹⁸ The victims had all chosen to be designated as do-not-resuscitate (DNR) patients, meaning that in case of catastrophic change in health, such as a heart attack or stroke, there was a standing order to medical staff to abstain from delivering lifesaving measures.¹⁹ Nevertheless, none of these patients had suffered such incidents. No one had warned them that under the circumstances of a natural disaster, the term DNR would take on a new meaning – do not rescue.²⁰ The charges against the two nurses for second-

12. LEX FRIEDMAN, NATIONAL COUNCIL ON DISABILITY, THE IMPACT OF HURRICANES KATRINA AND RITA ON PEOPLE WITH DISABILITIES: A LOOK BACK AND REMAINING CHALLENGE (2006).

13. *Freeman v. State*, 982 So. 2d 903, 907 (La. Ct. App. 2008).

14. Friedman, *supra* note 12.

15. Associated Press, *Katrina Victim Who Dies in Wheelchair Honored*, NBC NEWS (Sept. 1, 2006, 6:09 PM), <https://www.nbcnews.com/id/wbna14627601#.WI04ZvkrLIU>. See also Satz, *supra* note 8, at 10.

16. *Freeman*, 982 So. 2d at 908.

17. Charles I. Lugosi, *Natural Disaster, Unnatural Deaths: The Killings on the Life Care Floors at Tenet’s Memorial Medical Center After Hurricane Katrina*, 23 ISSUES L. & MED. 71, 72 (2007). See also Satz, *supra* note 8, at 10. See generally SHERI FINK, FIVE DAYS AT MEMORIAL: LIFE AND DEATH IN A STORM-RAVAGED HOSPITAL (2013).

18. Lugosi, *supra* note 17, at 72.

19. *Id.* at 74.

20. *Id.* at 76.

degree murder were later dropped,²¹ and a grand jury refused to indict Dr. Anna Pou for second-degree murder and nine counts of conspiracy to commit second-degree murder.²² And while this story surely raises ethical dilemmas about patient autonomy, “mercy killing,” and physicians’ liability,²³ it also brings to the surface common notions about the devaluation of disabled Black bodies among those working in the medical profession.

Both the Estel Freeman and the Memorial Medical Center incidents thus illustrate the racial dimensions of disability discrimination, the structural abandonment of Black communities around the events of Hurricane Katrina, and the racism/ableism framework Natalie Chin describes in her article for this Special Volume.²⁴

Seven years later, when Hurricane Sandy struck New York City in October 2012, and an evacuation notice was issued by then-Mayor Bloomberg, people with disabilities were found stranded once again. The city relied on public transportation as its primary means of evacuations during emergencies. Yet most of the public transportation in the city was not accessible to people with disabilities.²⁵ Paratransit, a service of accessible transportation, requires a twenty-four-hour advance reservation and is therefore inadequate during emergencies. In addition, paratransit began to shut down only half an hour after the mayor had issued the evacuation order, while other inaccessible means of public transportation remained open for at least eight additional hours.²⁶ Thousands of people with disabilities and older adults were left stranded

21. Associated Press, *Case Dropped Against Nurses for Katrina Deaths*, NBC NEWS (July 3, 2007, 2:53 PM), www.nbcnews.com/id/wbna19584941.

22. Peggy Peck, *Grand Jury Refuses to Indict New Orleans Doctor Charged with Killing Katrina-Stranded Patients*, MEDPAGE TODAY (July 25, 2007), <https://www.medpagetoday.com/publichealthpolicy/publichealth/6251>.

23. The decision not to indict Dr. Pou was supported by many in the medical profession. See Liam Bailey, *The Case of Dr. Anna Pou-Physician Liability in Emergency Situations*, 12 VIRTUAL MENTOR: AM. MED. ASS’N J. ETHICS 726, 729 (2010).

24. See generally Chin, *supra* note 9; For literature highlighting the importance of surfacing race and disability in discussions of disability discrimination see generally Beth Ribet, *Surfacing Disability Through A Critical Race Theoretical Paradigm*, 2 GEO. J.L. & MOD. CRITICAL RACE PERSP. 209 (2010); Adrienne Asch, *Critical Race Theory, Feminism, and Disability: Reflections on Social Justice and Personal Identity*, 62 OHIO ST. L.J. 391(2001); Jamelia Morgan, *Toward a Disability Critical Race Theory (DisCrit) Approach to American Law*, in DISCRIT EXPANDED: INQUIRIES, REVERBERATIONS & RUPTURES (Subini Annamma, David Connor & Beth Ferri, eds.) (forthcoming 2021); Jasmine E. Harris, *Reckoning with Race and Disability*, 130 YALE L.J. F. 916 (2021).

25. *Brooklyn Ctr. for Independent. of the Disabled v. Bloomberg*, 980 F. Supp. 2d 588, 605 (S.D.N.Y. 2013).

26. *Id.* at 644.

in apartment buildings or nursing homes without working elevators, medical assistance, running water, and electricity and with very little food²⁷ for nearly two weeks.²⁸ Under these circumstances, the District Court for the Southern District of New York concluded that the city had failed to provide people with disabilities meaningful access to its emergency preparedness program, in violation of the ADA and Section 504 of the Rehabilitation Act.²⁹

Fast-forward another seven years, in October 2019, amid the massive wildfires burning through California.³⁰ More than two million people faced deliberate power shutoffs made in an attempt to prevent electrical equipment from igniting the fires.³¹ In this instance too, people with disabilities were specifically disadvantaged. They were not given any advance notice about the blackouts by the power companies, leaving many rushing to find solutions to keep their medicines refrigerated and their electric wheelchairs and ventilators charged and to allow for air purification to be maintained in their homes.³² One woman with multiple sclerosis said that when she was ordered to evacuate, during an unexpected power shutoff, her car was trapped behind her electric garage door, which she was unable to lift on her own. Luckily, she was eventually saved by a passerby.³³ As the late disability justice activist Stacey Milbern recounted in a vigil held in front of the Pacific Gas and Electric Company (PG&E) offices in Oakland on October 10, 2019:

This week in the Bay Area, disabled people and elders without power are having difficulty breathing, moving, eating, and staying alive. A friend is going without her nebulizer treatments. A neighbor didn't have a way to store his insulin . . . Have you tried communicating in

27. Weibgen, *supra* note 7, at 2439; Jennifer Preston, Sheri Fink & Michael Powell, *Behind a Call that Kept Nursing Home Patients in Storm's Path*, N.Y. TIMES (Dec. 2, 2012), <https://www.nytimes.com/2012/12/03/nyregion/call-that-kept-nursing-home-patients-in-sandys-path.html>.

28. Weibgen, *supra* note 7, at 2441.

29. Brooklyn Ctr. for Independen. of the Disabled, 980 F. Supp. 2d at 658.

30. Jaelyn Cosgrove, *These Are the Largest Wildfires Burning in California Now*, L.A. TIMES (Oct. 9, 2019, 7:40 PM), <https://www.latimes.com/california/story/2019-09-10/fires-california-wildfire-season-now>.

31. Emma Newburger, *More Than 2 Million People Expected to Lose Power in PG&E Blackout As California Wildfires Rage*, CNBC NEWS (Oct. 26, 2019, 2:26 PM), <https://www.cnn.com/2019/10/26/pge-will-shut-off-power-to-940000-customers-in-northern-california-to-reduce-wildfire-risk.html>.

32. Colleen Shalby, *Power Outages Leave Those with Disabilities Especially Vulnerable. Help Remains a Work in a Progress*, L.A. TIMES (Oct. 25, 2019, 12:33 PM), <https://www.latimes.com/california/story/2019-10-25/problems-disabled-help-power-outages>.

33. *Id.*

American Sign Language in the dark? Not easy. I myself use life sustaining medical equipment, my ventilator, 16 hours a day. My doctor completed extensive paperwork telling pg&e why I need power to live . . . On Tuesday I called pg&e to ask for protocol for medical baseline users. I was on hold for two hours and twenty minutes. I hadn't received any notice from pg&e but saw my house on every map as about to lose power. When I was finally connected, the representative confirmed there was nothing really in place [for me to get a notice].³⁴

Then, in March 2020, the COVID-19 pandemic hit, reexposing the same pattern of mistreatment of people with disabilities in emergencies.³⁵ In his essay for this symposium, Sam Bagenstos described how a “herd immunity” strategy endorsed by the Trump administration, leaning toward reopening the economy and allowing spread of the virus, subordinated the interests of people with disabilities and older adults.³⁶ Another type of these “new eugenics” policies were the triage protocols found in state Crisis Standards of Care (CSC). These plans came under increased scrutiny from disability activists after it became clear that the pandemic was likely to bring widespread shortages of lifesaving medical resources, specifically ventilators. Activists and scholars criticized plans that sent disabled patients to the “back of the line” in the allocation of lifesaving medical treatment in an event of scarcity. This was carried out both through explicitly placing disabled patients at the bottom of the triage priority in certain state CSC protocols and by creating disparate impact through the application of facially neutral criteria that disproportionately deprioritized disabled patients in other states.³⁷ After filing complaints with the department of Health and Human Services’ Office for Civil Rights, disability rights organizations worked together with the federal agency to reach resolutions with states whose CSC guidelines were of particular concern.³⁸ New

34. Stacey Milbern, *We Need Power to Live*, DISABILITY VISIBILITY PROJECT (Oct. 13, 2019), <https://disabilityvisibilityproject.com/2019/10/13/we-need-power-to-live/>.

35. Harris, *supra* note 7, at 33.

36. Samuel R. Bagenstos, *The New Eugenics*, 71 SYRACUSE L. REV. 747 (2021).

37. Samuel R. Bagenstos, *Who Gets the Ventilator? Disability Discrimination in COVID-19 Medical-Rationing Protocols*, 130 YALE L.J. F. 1, 6 (2020); Laura Guidry-Grimes et al., *Disability Rights as a Necessary Framework for Crisis Standards of Care and the Future of Health Care*, 50 HASTINGS CENT. REP. 28, 28–29 (2020).

38. Doron Dorfman, *How an Unexpected Collaboration Led Utah to Amend Its Discriminatory Triage Plan*, THE HILL (Aug. 28, 2020, 2:30 PM), <https://thehill.com/opinion/civil-rights/514146-how-an-unexpected-collaboration-led-utah-to-amend-its-discriminatory>.

empirical research, surveying CSC across time, has shown that eighteen states revised their CSCs over the course of the pandemic in ways that respond to disability rights critiques.³⁹ These events demonstrate how a collaborative effort made by a coalition of disability organizations and the federal government can yield crucial accomplishments in the medical-legal realm. Other issues related to the COVID-19 pandemic, from the grave toll of the coronavirus on people with intellectual and developmental disabilities (IDD) in group homes and institutions,⁴⁰ to the lower priority given to non-elderly disabled individuals in the vaccine distribution,⁴¹ are reminders of the structural failures to protect this group. The story of Michael Hickson brings to light the racial dimension of disability discrimination⁴² in circumstances that are somewhat reminiscent of the Memorial Medical Center event during Hurricane Katrina.⁴³ Hickson, a forty-six-year-old Black man who was hospitalized due to complications from COVID-19, died after a court-appointed guardian decided to discontinue his life support treatment after consulting with the doctors, despite his wife's objection. Prior to his death, Hickson's wife recorded a conversation she had had with his doctor, which reflect her

39. Ari Ne'eman, Michael Ashley Stein, Zackary D. Berger & Doron Dorfman, *The Treatment of Disability Under Crisis Standards of Care: An Empirical and Normative Analysis of Change Over Time During COVID-19*, J. HEALTH POL. POL'Y & L. 1, 18 (2021).

40. See Scott Landes et al., *COVID-19 Outcomes Among People with Intellectual and Developmental Disability Living in Residential Group Homes in New York State*, 13 DISABILITY & HEALTH J. 1 (2020); Margaret A. Turk et al., *Intellectual and Developmental Disability and COVID-19 Case-Fatality Trends: TriNetX Analysis*, 13 DISABILITY & HEALTH J. 1 (2020); Scott Landes, et al., *People with Disabilities in COVID-19: Fixing Our Priorities*, 7 AM. J. BIOETHICS 187, 188 (2020).

41. MaryBeth Musumeci & Priya Chidambaram, *COVID-19 Vaccine Access for People with Disabilities*, KAISER FAM. FOUND. (March 1, 2021), <https://www.kff.org/medicaid/issue-brief/covid-19-vaccine-access-for-people-with-disabilities/> (stating that “less attention has been paid to nonelderly people with disabilities who use long-term services and supports (LTSS) but live outside of nursing homes Seniors in nursing homes are explicitly included in the top priority group in all states’ COVID-19 vaccine distribution plans, but nonelderly people with disabilities who use LTSS may be not prioritized.”); see also Sonja Sharp, *Californians with Disabilities are Outraged Over Vaccine De-Prioritization*, L.A. TIMES (Feb. 2, 2021, 5:00 AM), <https://www.latimes.com/california/story/2021-02-02/disabled-californians-outraged-vaccine-de-prioritization>.

42. A court appointed a guardian to make end-of-life decisions for Mr. Hickman while the guardianship cases filed by his wife was pending in court. Kim Roberts, *Austin Hospital Withheld Treatment from Disabled Man Who Contracted Coronavirus*, TEXAN (June 29, 2020), <https://thetexan.news/austin-hospital-withheld-treatment-from-disabled-man-who-contracted-coronavirus/>; see also Chin, *supra* note 9, at 729–30.

43. See *infra* notes 44–46 and accompanying text.

concern that the “doctors were placing less value on her husband’s life because he was a Black man who was disabled.”⁴⁴

When severe winter weather hit Southern states such as Texas and Mississippi in February 2021, it was a perfect storm of a global pandemic combined with the effects of climate change. Similar to what happened with the California wildfires, lack of electricity (this time in the freezing cold in states without proper infrastructure) had a disproportionate effect on people with disabilities.⁴⁵ Twenty-five-year-old Rafael Garcia from San Antonio, Texas, who lives with spinal muscular dystrophy, had to ration his time on his breathing machine because of limited access to power. As he describes it: “I had gone a full 24 hours without my breathing treatments, which keep my airwaves open. I remember thinking, ‘OK Ralph, you gotta keep breathing. You can’t have an asthma attack. You can’t panic.’”⁴⁶

This incomplete history displays the devaluation of disabled lives in times of emergencies. As Judge Jesse M. Furman of the District Court for the Southern District of New York stated in a class action suit against the City of New York in regard to its actions during Hurricane Sandy: “The needs of people with disabilities . . . [can] only be accommodated through advance planning . . . *ad hoc* accommodations ‘are both legally inadequate and practically unrealistic.’”⁴⁷ Scholars and courts have generally interpreted Title II of the ADA and section 504 of the Rehabilitation Act, which prohibit disability discrimination by state and

44. Ariana E. Cha, *Quadriplegic Man’s Death from Covid-19 Spotlights Questions of Disability, Race and Family*, WASH. POST (July 5, 2020, 9:40AM), <https://www.washingtonpost.com/health/2020/07/05/coronavirus-disability-death/>.

45. See generally Katie Reilly, *Texas Republican Leadership Failed Disabled People During Winter Storm Disaster*, TEEN VOGUE (Feb. 25, 2021), <https://www.teenvogue.com/story/texas-republican-leadership-failed-disabled-people>; Amal Ahmed, *Texans With Disabilities Were Left to Fend for Themselves During Winter Storm Uri*, TEXAS OBSERVER (April 15, 2021), <https://www.texasobserver.org/texans-with-disabilities-were-left-to-fend-for-themselves-during-winter-storm-uri/>.

46. Miguel Perez, *‘We Have No Safety Net’: Disability Rights Advocates Speak Out After Winter Storm*, KERA NEWS (Feb. 26, 2021), <https://www.keranews.org/news/2021-02-26/we-have-no-safety-net-disability-rights-advocates-speak-out-after-winter-storm>; see also St. John Bamed-Smith, *‘I don’t know who cares about us’: How Texas failed people with disabilities during the freeze*, HOUS. CHRON. (April 7, 2021), [https://www.houstonchronicle.com/news/houston-texas/houston/article/I-don-t-know-who-cares-about-us-How-16084345.php?utm_campaign=CMS%20Sharing%20Tools%20\(Premium\)&utm_source=t.co&utm_medium=referral](https://www.houstonchronicle.com/news/houston-texas/houston/article/I-don-t-know-who-cares-about-us-How-16084345.php?utm_campaign=CMS%20Sharing%20Tools%20(Premium)&utm_source=t.co&utm_medium=referral).

47. *Brooklyn Ctr. for Independen. of the Disabled v. Bloomberg*, 980 F. Supp. 2d 588, 644 (S.D.N.Y. 2013).

local governments and by federally funded programs, respectively, as applying to emergency plans.⁴⁸

Nevertheless, these legal tools seem to largely be at work *ex post* in the context of alleged violations of these disability discrimination statutes. An imagined future for the ADA, as I see it, would include a specific title in the ADA on emergency relief. The inspiration for drafting such title could come from the UN Convention on the Rights of People with Disabilities (CRPD). Article 11 of the CRPD requires state parties to “take all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including . . . humanitarian emergencies and the occurrence of natural disasters.”⁴⁹ Such title should be accompanied by the promulgation of implementing regulations. Those provisions would work to instruct and serve as a checklist for the federal, state, and local governments to implement in constructing their emergency plans, similar to accessibility standards for the physical environment articulated in the regulations for Title II and Title III.⁵⁰ The addition of an emergency relief title in the ADA would also be relevant, as calls to recognize climate change as a national security issue⁵¹ have been made alongside the need to align issues of environmental justice with those of disability justice. This new title in the ADA would thus provide the appropriate safety net to people with disabilities, as emergencies likely become increasingly frequent in our lifetime.

Such regulations would not only include the general prohibition of discrimination but also provide, for example, the number of accessible vehicles used for evacuation (in relation to the city’s population), ways

48. *Cmtys. Actively Living Indep. & Free v. City of Los Angeles*, No. CV 09-0287 CBM (RZx), 2011 WL 4595993 at *42, *49 (C.D. Cal. Feb. 10, 2011) (Where the District Court for the Central District of California found that the emergency preparedness program of the City of Los Angeles failed to include provisions to notify people, communicate, evacuate, transport, or temporarily house people with disabilities during an emergency. The court applied the antidiscrimination of Title II to the ADA and Section 504 concluding “that individuals with disabilities are disproportionately burdened by the City’s failure to consider their unique needs in the administration of its emergency preparedness program,” *id.* at *42); Bagenstos, *supra* note 37, at 5–6; Deborah Hellman & Kate Nicholson, *Rationing & Disability: The Civil Rights and Wrongs of State Triage Protocols*, WASH. & LEE L. REV. (forthcoming 2021); Ne’eman, Stein, Berger & Dorfman, *supra* note 39, at 10.

49. United Nations, Convention on the Rights of Persons with Disabilities art. 11, Dec. 13, 2006, 2515 U.N.T.S. 3.

50. Title II and III are implemented through regulations that come to ensure nondiscrimination in all services, programs, and activities provided to the public by state and local governments under Title II and in places of public accommodation and commercial facilities under Title III. *See* 28 C.F.R. §§ 35.106, 36.102.

51. Mark Patrick Nevitt, *On Environmental Law, Climate Change, & National Security Law*, 44 HARV. ENV’L L. REV. 321, 328 (2020).

to distribute generators to people dependent on power during expected shutoffs, the creation of lifesaving reserves,⁵² a procedure to ensure equitable vaccine distribution, and standards to ensure clear communications to people with hearing impairments and IDD during an emergency, among other requirements. The regulations could make use of centers of independent living, statutory entities that are spread out across the country and that provide services to and guidance for people with disabilities.⁵³ Those centers may be converted into shelters in an emergency or used to distribute resources and supplies. The involvement of the centers for independent living during emergencies would also ensure input by people with disabilities themselves, as they are the ones operating those centers. The expertise of disabled people and their lived experiences should help guarantee that the emergency plans are comprehensive and practical.⁵⁴

II. ENSURING ACCESS TO PHYSICAL AND ONLINE ENVIRONMENTS

As Mariela Yabo and I argued in a different article, disability access law has a compliance problem.⁵⁵ The scope of Title II and Title III to the ADA is broad. Together they require compliance with accessibility standards, laid out in detailed regulations, to remove architectural barriers from both governmentally owned buildings and privately operated places of public accommodation.⁵⁶ Yet issues of access to built environments abound in all areas of life.

52. During the early days of the COVID-19 pandemic, people living with lupus had a difficult time accessing the drug hydroxychloroquine, which is critical for them, as President Trump falsely declared it as a cure to coronavirus. In response, some insurance companies refused to refill prescriptions to people with lupus and gave COVID patients priority, see Chinyere Amobi, *Left Behind: The Pandemic Revealed How the U.S. Really Thinks About its Chronically Ill*, CTR. FOR HEALTH JOURNALISM (March 8, 2021), <https://centerforhealthjournalism.org/2021/03/05/left-behind-pandemic-revealed-how-us-really-thinks-about-its-chronically-ill>. Creating a medication reserve should help resolve such incidents.

53. 29 U.S.C. § 796a (2021) (“the term ‘center for independent living’ means a consumer-controlled, community-based, cross-disability, nonresidential private nonprofit agency for individuals with significant disabilities (regardless of age or income) that— (A) is designed and operated within a local community by individuals with disabilities; and (B) provides an array of independent living services, including, at a minimum, independent living core services...”); For a list of Centers for Independent Living across the country, see ILRU DIRECTORY OF CTRS FOR INDEP. LIVING (CILS) AND ASS’N, <https://www.ilru.org/projects/cil-net/cil-center-and-association-directory> (last visited Sept. 17, 2021).

54. Weibgen, *supra* note 7, at 2468. For the importance of leveraging the expertise of disabled people in the policies at the municipal level, see Doron Dorfman & Mariela Yabo, *The Professionalization of Urban Accessibility*, 47 *FORDHAM URB. L.J.* 1213, 1254 (2020).

55. Dorfman & Yabo, *supra* note 54, at 1214.

56. *Id.* at 1223–25.

It's been more than three decades since the enactment of the ADA, yet simply getting around New York City, for example, proves to be a challenging task for anyone living with sensory or mobility impairments. Sidewalks lack curb cuts or have ones that are not properly installed,⁵⁷ less than 25% of the subway stations are somewhat accessible to wheelchair users,⁵⁸ and only 3.4% of street intersections are equipped with audible devices that tell blind people and those with visual impairments when it is safe to cross.⁵⁹ And if sidewalk navigation was not difficult enough, in the summer of 2020, amid the COVID-19 pandemic, the access needs of people with disabilities were quite literally pushed aside to allow added sidewalk seating for restaurants in New York and other cities.⁶⁰ Across the country, hotel rooms⁶¹ and restaurants⁶² are inaccessible. Only in mid-2020, an elementary school in Rhode Island

57. Winnie Hu, *Disabled New Yorkers Face Trouble with the Curbs*, N.Y. TIMES (Oct. 9, 2017), <https://www.nytimes.com/2017/10/08/nyregion/new-york-city-sidewalks-disabled-curb-ramps.html>; Yochai Eisenberg, Amy Heider, Rob Gould & Robin Jones, *Are Communities in the United States Planning for Pedestrians with Disabilities? Findings from a Systematic Evaluation of Local Government Barrier Removal Plans*, 102 CITIES 3, 8–9 (2020).

58. By being “somewhat accessible,” it means that 13 of the 99 arguably accessible stations (out of a total 472 in all of New York City) “are, structurally, only partially accessible, in the sense that the elevators provide access to some but not all lines or platforms serviced by a particular station . . . [in addition], as users know far too well, the elevators are often out of service; according to one recent study, ‘on average, each subway elevator breaks down 53 times a year.’” See Elizabeth F. Emens, *The Art of Access: Innovative Protests of an Inaccessible City*, 47 FORDHAM URB. L.J. 1359, 1364 (2020).

59. In October 2020, the District Court for the Southern District of New York decided that this conduct amounted to a violation of Title II and Section 504 of the Rehabilitation Act, see *Am. Council of Blind of New York, Inc. v. City of New York*, 495 F. Supp. 3d 211, 221 (S.D.N.Y., Oct. 20, 2020).

60. Erika Mailman, *As Restaurants Take Over Sidewalks to Provide Pandemic-Safe Dining, People with Disabilities Encounter Barriers*, WASH. POST (August 23, 2020), https://www.washingtonpost.com/health/coronavirus-sidewalk-seating-disabilities-barriers/2020/08/21/02ede6b8-e24c-11ea-8181-606e603bb1c4_story.html?fbclid=IwAR3_jFMSJe3RSPoP-LBX0KuDY9m_jO-xGrdJi-hoKBzPrYw-ywP2qF_DTJc; Meghan Holohan, *‘I Am Not In the Way’: Outdoor Dining Adds Obstacles for People with Disabilities*, TODAY (Oct. 27, 2020, 9:59 AM), <https://www.today.com/health/outdoor-dining-adds-obstacles-people-disabilities-t196151>.

61. Vilissa Thompson, *(In)accessible Rooms: The Biggest Lie Told by the Hotel Industry*, RAMP YOUR VOICE! (Jan. 12, 2017, 12:30 PM), <http://www.rampyourvoice.com/inaccessible-rooms-biggest-lie-told-hotel-industry/>.

62. David Perry, *Restaurants Haven’t Lived Up to the Promise of the Americans with Disabilities Act*, EATER (May 31, 2017, 9:28 AM), <https://www.eater.com/2017/5/31/15701042/american-disabilities-act-restaurants-compliance>.

began the final stages of installing an elevator to comply with Title II.⁶³ As Prianka Nair has discussed in her article for this Special Volume, disabled inmates also suffer from lack of access to various programs and services because of the inaccessibility of their prison environments.⁶⁴

What these few examples highlight is that the work to ensure accessibility has not been enforced in a way to actually guarantee access to and usability by disabled individuals. The enforcement of comprehensive standards of the Title II and Title III regulations is done almost exclusively through private litigation, and only after the construction of the space or the building is complete and not earlier, at the design stage.⁶⁵ Despite that the ADA requires the United States Department of Justice (DOJ) to review and investigate claims of non-compliance with the ADA accessibility standards,⁶⁶ most enforcement falls upon individual litigants acting as “private attorneys general.”⁶⁷ Yet the ADA provides weak incentives for such private litigants enforcing

63. Keldy Ortiz, *Work Resumes on Elevator Installation at West Babylon Elementary School*, *NEWSDAY* (June 10, 2020, 3:43 PM), <https://www.newsday.com/long-island/suffolk/elevator-elementary-school-covid-19-americans-with-disabilities-act-1.45559721>.

64. Parnika Nair, *The ADA Constrained: How Federal Courts Dilute the Reach of the ADA in Prison Cases*, 71 *SYRACUSE L. REV.* 787, 805–809 (2021); see also Jamelia Morgan, *Caged In: The Devastating Harms of Solitary Confinement on Prisoners with Physical Disabilities*, 24 *BUFF. HUM. RTS. L. REV.* 81, 84 (2017–2018) (stating that “[p]risoners and detainees with disabilities may be placed into solitary confinement because there are no accessible housing units in which to hold them, as in the case of prisoners who use wheelchairs”).

65. Dorfman & Yabo, *supra* note 54, at 1239.

66. 42 U.S.C. § 12188(b)(1)(A)(i) (2006). Title III also authorizes the U.S. Attorney General to sue for violations that constitute either a pattern or practice of discrimination or which raise an issue of general public importance. 42 U.S.C. § 12188(b)(2)(B) (2006). Under Title II, an individual may file a complaint with the DOJ or other appropriate agency, which then must investigate the complaint and attempt to reach an informal resolution. If informal resolution fails and the applicable agency finds noncompliance, it refers the complaint to the DOJ, which attempts to negotiate compliance and potentially files suit. See also Michael Waterstone, *The Untold Story of the Rest of the Americans with Disabilities Act*, 58 *VAND. L. REV.* 1807, 1865–66 (2005).

67. Michael Waterstone, *A New Vision of Public Enforcement*, 92 *MINN. L. REV.* 434, 447–48 (2007). As Sam Bagenstos notes:

[T]he U.S. Department of Justice has devoted ‘only a small cadre of lawyers’ to disability rights enforcement, and those lawyers must shoulder responsibility for enforcing the ADA against state and local governments as well as against private businesses. . . . Because the government does not fully enforce the ADA, private enforcement is essential.

See Samuel R. Bagenstos, *The Perversity of Limited Civil Rights Remedies: The Case of “Abusive” ADA Litigation*, 54 *UCLA L. REV.* 1, 9–10 (2006).

accessibility in places of public accommodation under Title III.⁶⁸ Litigants may only receive injunctive relief and limited attorney fees and cannot recover monetary compensation.⁶⁹ This is due to a “fragile compromise” made at the time of the ADA’s enactment: limited remedies in exchange for an expansive list of commercial entities covered as places of public accommodation.⁷⁰ Moreover, as Steven Schwartz and Kathryn Rucker discuss in this Special Volume, class action relief is also difficult, if not impossible, to obtain today in the post-*Walmart v. Dukes* era.⁷¹

This hands-off approach to ensuring accessibility of the physical environment has been referred to as a “diffused model” of enforcement; the issue of providing incentives for private litigants is left to the discretion of states and municipalities, and each takes a different approach.⁷² Yet many gaps remain in a world designed with people with disabilities being, at best, an afterthought.⁷³

Accessibility of online environments fares even worse under the ADA. In July 1990, when the ADA was originally signed into law, the commercial internet, as we know it today, did not exist.⁷⁴ Thus, over the years, circuit courts debated the question of whether the accessibility standards of Title II and Title III apply to cyberspace. The debates focused on the question of whether websites can be considered places of

68. Bagenstos, *supra* note 67, at 11–13.

69. 42 U.S.C. § 12188(a)(1) (2018); 28 C.F.R. § 36.501(a) (1991) (“Any person who is being subjected to discrimination on the basis of disability in violation of the Act or this part or who has reasonable grounds for believing that such person is about to be subjected to discrimination in violation of section 303 of the Act or subpart D of this part may institute a civil action for preventive relief, including an application for a permanent or temporary injunction, restraining order, or other order.”).

70. Ruth Colker, *ADA Title III: A Fragile Compromise*, 21 BERKELEY J. EMP. & LAB. L. 377, 383 (2000).

71. Steven Schwartz & Kathryn Rucker, *The Commonality of Difference: A Framework for Obtaining Class Certification in ADA Cases After Walmart*, 71 SYRACUSE L. REV. 835 (2021).

72. Dorfman & Yabo, *supra* note 54, at 1240, 1242.

73. TANYA TITCHKOSKY, A QUESTION OF ACCESS: DISABILITY, SPACE, MEANING 78 (2011); TOBIN SIBERS, DISABILITY THEORY 75–79 (2008); Sagit Mor, *With Access and Justice for All*, 39 CARDOZO L. REV. 611, 612–13 (2017).

74. Blake Reid, *Internet Architecture & Disability*, 95 INDIANA L.J. 591, 596 (2020).

public accommodation even though they do not inhabit physical space or have a nexus to one.⁷⁵ There is currently a circuit split on this issue.⁷⁶

In October 2019, the Supreme Court denied certiorari⁷⁷ in *Robles v. Domino's Pizza*.⁷⁸ In this case, the Ninth Circuit required the fast-food chain to make its website accessible to customers with visual impairments, as those serve as gateways to a physical store.⁷⁹ Many disability advocates were relieved by the Supreme Court's denial to hear an appeal, as they had felt it was highly likely the Court would have reversed the decision and put an end to the chances of a broader interpretation of the ADA being made by certain circuits – requiring web accessibility.⁸⁰

In April 2021, the Eleventh Circuit reached a different conclusion, namely that websites operated by businesses are not places of public accommodation under Title III of the ADA. In *Gil v. Winn-Dixie*, the court concluded that the grocery store chain's website was not a point of sale (as all purchases must be completed at the store) and did not present an “intangible barrier” to shopping for goods and services at Winn-Dixie's physical stores.⁸¹ Although this decision may be viewed as a narrow holding limited to the unique facts at hand,⁸² it clearly demonstrates the circuit split on an issue that has become even more

75. See, e.g., *Access Now v. Southwest Airlines*, 227 F. Supp. 2d 1312, 1321 (S.D. Fla. 2002) (where the court concluded that Title III does not apply to the commercial airline website as “the Internet website at issue here is neither a physical, public accommodation itself as defined by the ADA, nor a means to accessing a concrete space”). See also PETER BLANCK, EQUALITY: THE STRUGGLE FOR WEB ACCESSIBILITY BY PERSONS WITH COGNITIVE DISABILITIES 82 (2014); Reid, *supra* note 74, at 597-99.

76. Reid, *supra* note 74, at 597.

77. *Robles v. Dominos Pizza*, 913 F.3d 898 (9th Cir., 2019), *cert. denied*.

78. *Id.* at 911.

79. *Id.* at 905. The Ninth Circuit interpreted Title III to prohibit discrimination on the basis of disability by requiring places of public accommodation to provide appropriate auxiliary aids and services when necessary to ensure effective communication to guarantee individuals with disabilities have full and equal enjoyment of their websites as individuals without disabilities do. *Id.* at 904, 907.

80. See, e.g., Lainey Feingold, *U.S. Supreme Court Won't Hear The Domino's Case (Hooray!)*, LAW OFFICE OF LAINEY FEINGOLD (October 7, 2019) (stating “All we know is that the highest court in the United States will not rule (at least in the Domino's case) on website or mobile accessibility lawsuits under the ADA. And that the Ninth Circuit's opinion in favor of ADA coverage of websites and mobile apps remains good law. Whew!!”).

81. *Gil v. Winn-Dixie Stores, Inc.*, No. 17-13467, 2021 WL 1289906, at *1275 n.8 (11th Cir., 2021).

82. *Id.* at *1281 n.19.

pressing with the rise in telehealth during the COVID-19 pandemic.⁸³ The DOJ's approach has been generally supportive of reading Title II and Title III as applied to websites.⁸⁴ The DOJ has also been regularly filing amicus briefs and negotiating settlements in web accessibility cases.⁸⁵ Nevertheless, it seems as though the solution to ending the ambiguity around the applicability of the ADA's accessibility mandates to online environments should be achieved via congressional intervention, which would resolve this statutory interpretation question.

An imagined future for the ADA in terms of ensuring the implementation of accessibility mandates, both in the physical and the online environments, requires a move from a hands-off "diffused model" approach to a more centralized model for ensuring compliance with accessibility codes.

In regard to the built environment, Mariela Yabo and I suggested that this kind of move could be carried out by ensuring accessibility of new construction at the design stage when approving plans, a process that has been ongoing in some, but not all, major American cities. While specifics of what such a licensing process should precisely entail could be left to state law, the mandate to require such a license should be enacted at the federal level. Regulating such a licensing process in the ADA would ensure that access is dealt with *ex ante*, at the design stage, instead of *ex post*, through litigation.⁸⁶ A more centralized model for enforcing accessibility in existing construction means creating state commissions that would not rely primarily on private litigants but would rather employ accessibility professionals who ensure compliance and file complaints themselves. This model of enforcement has been successful

83. See generally Thiru M. Annaswamy, Monica Verduzco-Gutierrez & Lex Frieden, *Telemedicine Barriers and Challenges for Persons with Disabilities: COVID-19 and Beyond*, 13 DISABILITY & HEALTH J. (2020); Laura C. Hoffman, *Shedding Light on Telemedicine & Online Prescribing: The Need to Balance Access to Health Care and Quality of Care*, 46 AM. J.L. & MED. 237, 237 (2020); Robyn M. Powell, *Applying the Health Justice Framework to Address Health and Health Care Inequities Experienced by People with Disabilities During and After COVID-19*, 96 WASH. L. REV. 93, 133–34 (2021).

84. "The Department first articulated its interpretation that the ADA applies to public accommodations' websites over 20 years ago. This interpretation is consistent with the ADA's title III requirement that the goods, services, privileges, or activities provided by places of public accommodation be equally accessible for people with disabilities." See Letter from Stephen E. Boyd, Assistant Att'y Gen., to Rep. Ted Budd, (Sept. 25, 2018), <https://www.adatitleiii.com/wp-content/uploads/sites/121/2018/10/DOJ-letter-to-congress.pdf>.

85. Reid, *supra* note 74, at 600.

86. Dorfman & Yabo, *supra* note 54, at 1253–54.

abroad.⁸⁷ As Michael Waterstone envisioned, this type of new governance, embodied in those state commissions, allows reforms and compliance schemes through information sharing and through state-sponsored litigation that works alongside private litigation. Yet such litigation would no longer be the primary vehicle for vindicating access rights.⁸⁸ Altering the incentives for private litigants by allowing monetary damages is tricky considering the backlash that has arisen against private litigants in this context, often portrayed as abusive and engaging in “drive-by lawsuits.”⁸⁹ The creation of a centralized, state-sponsored system within the ADA, itself, might help normalize the practice of enforcing accessibility and reduce the existing stigma against private litigants in this context.

In regard to online environments, Congress should therefore amend the definition of “places” and “services” under Titles II and III to include websites, apps, and other online environments. Such a clarification regarding the proper interpretation of definitions under the ADA would not be the first, considering the ADAAA that came after the backlash against the enactment of the ADA in the late 1990s and early 2000s.⁹⁰ Such an amendment to the ADA would require great bipartisan support

87. Like in Israel that modeled its main disability antidiscrimination law after the ADA yet took a more hands-on approach to enforcement. *See id.* at 1229, 1231, 1249.

88. Waterstone, *supra* note 67, at 485.

89. Ruth Colker, *The Power of Insults*, 100 B.U. L. REV. 1, 38–39 (2020); Bagenstos, *supra* note 67, at 4–5, 26; Dorfman & Yabo, *supra* note 54, at 1242. *See also* Lauren Markham, *The Man Who Filed More Than 180 Disability Lawsuits: Is it Profiteering – Or Justice?* N.Y. TIMES MAGAZINE (Aug. 29, 2021), <https://www.nytimes.com/2021/07/21/magazine/americans-with-disabilities-act.html>; Carri Becker, *Private Enforcement of the American with Disabilities Act via Serial Litigation: Abusive or Commendable?*, 17 HASTINGS WOMEN'S L.J. 93, 97 (2006); Katherine Pankow, *Advocates for the Disabled, or Extortionist Vampires? Chapter 383 Attempt to Prevent Plaintiffs' Attorneys from Bleeding Small Businesses Dry*, 44 MCGEORGE L. REV. 559, 559–60 (2013); Casey L. Raymond, *A Growing Threat to the ADA: An Empirical Study of Mass Filings, Popular Backlash, and Potential Solutions under Title II and III*, 18 TEX. J. ON C. L. & C. R. 235, 244–45 (2013); Linda H. Wade & Timothy J. Inacio, *A Man in a Wheelchair and His Lawyer Go into a Bar: Serial ADA Litigation Is No Joke*, 25 TRIAL ADVOC. Q. 31, 33 (2006). This is another manifestation of the socio-legal phenomenon I term “fear of the disability con,” in other words, the notion that there is a widespread abuse of disability rights and privilege by those seeking an unfair advantage. *See* Doron Dorfman, *Fear of the Disability Con: Perceptions of Fraud and Special Rights Discourse*, 53 LAW & SOC'Y REV. 1051, 1060–62 (2019); Doron Dorfman, *[Un]Usual Suspects: Deservingness, Scarcity, and Disability Rights*, 10 U.C. IRVINE L. REV. 557, 567–68 (2020).

90. The amendment came to instruct courts that the meaning of “disability” should be interpreted broadly to fit with original congressional intent after courts have interpreted it to be a demanding standard that prevented standing from many plaintiffs. 42 U.S.C. § 12102(3)(A) (2021); *see also* Elizabeth F. Emens, *Disability Attitudes: U.S. Disability Law and the Amendment Act*, 60 AM. J. COMP. L. 205, 212–13 (2012).

that would need to stand up to powerful lobbyists employed by business owners. This type of change would depend, therefore, on a societal change in attitudes regarding both disability and accessibility or, as Liz Emens referred to it in this Special Volume, on more people “getting it.”⁹¹ One could hope that the shift and dependence on online environments that occurred during the COVID-19 pandemic would help foster such a move. I would also argue that subsidies offered to smaller businesses to comply with the new online accessibility requirements, specifically in jurisdictions where the courts have not supported such requirements under the current definition, might be warranted. Such subsidies are, of course, a tricky issue in our current legal system that is largely based on negative rights rather than positive rights. Yet it is part of this bigger vision for the ADA’s imagined future, one that I will elaborate on in the next section.

III. UNIVERSAL HEALTH CARE

As Arlene Kanter writes in her Introduction to this Special Volume,⁹² the ADA was meant to bring down “the shameful wall of exclusion,”⁹³ for “a discrete and insular minority . . . subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society.”⁹⁴ When first enacted, the ADA broke new ground in American legal tradition by combining a distributive element of “positive rights” into its antidiscrimination mandates, compelling state and private actors to affirmatively provide accommodations for people with disabilities.⁹⁵ This requirement is noteworthy because most American civil rights laws are based on the tradition of negative rights, prohibiting interference with private behavior.⁹⁶ As I have claimed

91. Elizabeth Emens, *Getting It: The ADA After Thirty Years*, 71 SYRACUSE L. REV. 637 (2021).

92. Arlene Kanter, *The ADA at Thirty: It’s Limits and Potential*, 71 SYRACUSE L. REV. 621 (2021).

93. To paraphrase President George H. W. Bush at the signing of the ADA who finished his remarks by saying: “Let the shameful wall of exclusion come tumbling down.” See Press Release, The White House Office of the Press Sec’y, Remarks by the President During Ceremony for the Signing of the Americans with Disabilities Act of 1990 (July 26, 1990), <https://www.archives.gov/research/americans-with-disabilities/transcriptions/naid-6037492-remarks-by-the-president-during-ceremony-for-the-signing-of-the-americans-with-disabilities-act-of-1990.html>.

94. 42 U.S.C. § 12101(a)(7) (repealed 2008).

95. 42 U.S.C. § 12183 (2021).

96. KATHARINA HEYER, RIGHTS ENABLED: THE DISABILITY REVOLUTION, FROM THE US, TO GERMANY AND JAPAN, TO THE UNITED NATIONS 44–45 (2015); Michael Ashley Stein & Penelope J.S. Stein, *Beyond Disability Civil Rights*, 58 HASTINGS L. J. 1203, 1209 (2006); ARLENE S. KANTER, THE DEVELOPMENT OF DISABILITY RIGHTS UNDER INTERNATIONAL LAW:

elsewhere, this notion of accommodations as positive rights has not yet caught on among the American public, unfortunately creating the perceptions of disability rights as “special rights” prone to abuse.⁹⁷ Nevertheless, part of “the difference that disability makes”⁹⁸ is the need to actively alter some policies, programs, and environments to allow for the inclusion of people with impairments.

Ultimately, as omnibus as it is, the ADA is an antidiscrimination law that does not account for health-care disparities for people with disabilities. In his 2004 article “The Future of Disability Law,” which addressed employment opportunities and integration of disabled people into the workforce, Sam Bagenstos famously pointed out the limitations of the ADA’s antidiscrimination framework.⁹⁹ He argued such an approach cannot do much to break down deep-rooted structural barriers that stand in the way of full inclusion.¹⁰⁰ Specifically, Bagenstos talked about health insurance coverage as “the most significant obstacle to entering the workforce that people with disabilities collectively face.”¹⁰¹ Written six years before the enactment of the Patient Protection and Affordable Care Act (ACA), that article focused on 1) the methods private insurers employ to discriminate against this population in offering insurance in the first place or in policy coverage,¹⁰² and 2) the limitations of private insurance for those employed and public insurance (Medicare and Medicaid) for disabled individuals who receive Social Security benefits.¹⁰³

FROM CHARITY TO HUMAN RIGHTS 3 (positive and negative rights embedded in international human rights law distinguished from U.S. civil rights law) (2015); Arlene S. Kanter, *The Americans with Disabilities Act at 25 Years: Lessons to Learn from the Convention on the Rights of People with Disabilities*, 63 DRAKE L. REV. 819, 881 (2015).

97. Dorfman, *supra* note 89, at 561–62.

98. To paraphrase the famous book by ROD MICHALCO, *THE DIFFERENCE THAT DISABILITY MAKES* (2002).

99. Similarly, Ani Satz also presented a critique to the antidiscrimination approach based on “fragmenting disability protection,” a legal approach that only provides protections in certain areas such as employment or public accommodations without taking into account the full lived experiences of people with disabilities. See Ani B. Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*, 83 WASH. L. REV. 513, 541 (2008).

100. Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1, 23 (2004). See also SAMUEL R. BAGENSTOS, *LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT* 136 (2009).

101. Bagenstos, *supra* note 100, at 6.

102. *Id.* at 27–28.

103. Specifically discussing how the fear of losing insurance through Medicaid and Medicare if getting employed disincentivized disabled individuals from entering the workplace, see *id.* at 32–34.

As Jessica Roberts has shown, the ACA has had a positive effect on people with disabilities.¹⁰⁴ The first problem Bagenstos raised regarding the denial of insurance altogether or limiting coverage due to disability has been addressed. The ACA incorporates an express antidiscrimination provision protecting people with disabilities among other protected groups. The provision applies to recipients of “credits, subsidies, or contracts of insurance” from the federal government.¹⁰⁵ Included in this category are private insurers (at least those offering plans on the exchanges),¹⁰⁶ who used to be the primary source of discrimination prior to the ACA’s enactment.¹⁰⁷ The ACA also requires insurers to alter their health plans to increase consumers’ coverage and choice. To that effect, the ACA has guaranteed that insurers cannot deny coverage to people with preexisting conditions based on health status, medical condition, medical history, genetic information, evidence of insurability, or disability.¹⁰⁸ Insurers must also offer premiums based on community ratings, in other words, at the same price to all persons regardless of their health status. Differentiation among the premiums can only be on the basis of age, geographic area, family composition, and tobacco use.¹⁰⁹ The ACA also prohibited imposing lifetime caps on benefits, in other words, imposing a dollar limit on what the insurer will spend for a covered benefit during the entire duration of the insurance coverage is no

104. Jessica L. Roberts, *Health Law as Disability Law*, 97 MINN. L. REV. 1962, 2031, 2035 (2013) (concluding that “[the] ACA can be read as conferring a number of rights and benefits on people with disabilities” and that “[t]he Affordable Care Act represents a sea change for people with disabilities”).

105. Patient Protection and Affordable Care Act, Pub. L. No. 111–148, § 2705, 124 Stat. 119, 119 (2010) (codified as amended at 42 U.S.C. 300gg–4); 42 U.S.C. § 18116(a) (2012).

106. A rule the Trump Administration established took the position that the language in section 1557 only applies to insurers’ plans offered on the exchanges, while any plans they offer or administer outside of the exchanges are not covered by section 1557. *See* 45 C.F.R. § 92.3(b) (2019) (“[H]ealth program or activity’ encompasses all of the operations of entities principally engaged in the business of providing healthcare that receive Federal financial assistance as described in paragraph (a)(1) of this section. For any entity not principally engaged in the business of providing healthcare, the requirements applicable to a ‘health program or activity’ under this part shall apply to such entity’s operations only to the extent any such operation receives Federal financial assistance as described in paragraph (a)(1) of this section.”); *see also id.* § 92.3(c) (“[A]n entity principally or otherwise engaged in the business of providing health insurance shall not, by virtue of such provision, be considered to be principally engaged in the business of providing healthcare.”). *See* Valerie K. Blake, *Health Care Civil Rights Under Medicare for All*, 72 HASTINGS L.J. 773, 798 (2021).

107. *Id.* at 798.

108. Patient Protection and Affordable Care Act § 2705, 124 Stat. at 156 (codified as amended at 42 U.S.C. § 300gg–4).

109. Patient Protection and Affordable Care Act, § 2701, 124 Stat. at 155 (codified as amended at 42 U.S.C. § 300gg (prohibiting discriminatory premium rates)).

longer allowed.¹¹⁰ The creation of the health insurance exchanges eradicated “thin health insurance plans” by guaranteeing that all plans provide “essential benefits.” Those essential benefits include “rehabilitative and habilitative services and devices (services and devices to help people with injuries, disabilities, or chronic conditions gain or recover mental and physical skills).”¹¹¹

Nevertheless, Bagenstos’s second concern, issues regarding health insurance availability to people with disabilities who are employed or receive Social Security benefits, persists, at least to some degree. Employment-sponsored insurance is the way most Americans receive health-care coverage.¹¹² As with most Americans who depend on their employer to cover their health insurance, beneficiaries of Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) are in a similar position. These beneficiaries rely on their eligibility for those Social Security programs for receiving public health insurance in the form of Medicare or Medicaid. Though historically Medicaid and Medicare failed to cover the health needs of people with disabilities, the Obama-era health-care reform improved services and support for home and community based services along with coverage of medical equipment.¹¹³

Eligibility for Medicare, a health insurance program funded and administered by the federal government for people sixty-five or older, and for younger people with disabilities or end-stage renal diseases, is attached to one’s eligibility for SSDI. A person eligible for SSDI, a social insurance program designed to support people with disabilities who are

110. Patient Protection and Affordable Care Act, § 2711, 124 Stat. at 131 (codified as amended at 42 U.S.C. § 300gg–11). “The current law bans annual dollar limits that all job-related plans and individual health insurance plans can put on most covered health benefits . . . Before . . . [the ACA] many health plans set an annual limit — a dollar limit on their yearly spending for your covered benefits. You were required to pay the cost of all care exceeding those limits.” Lifetime & Annual Limits, HHS, <https://www.hhs.gov/healthcare/about-the-aca/benefit-limits/index.html> (last visited Sept. 18, 2021).

111. *What Marketplace Health Insurance Plans Cover*, HEALTHCARE.GOV, <https://www.healthcare.gov/coverage/what-marketplace-plans-cover/> (last visited Sept. 18, 2021).

112. Chris Lee, *Coverage at Work: The Share of Nonelderly Americans with Employer-Based Insurance Rose Modestly in Recent Years, but Has Declined Markedly Over the Long Term*, KFF (Feb. 1, 2019), <https://www.kff.org/health-reform/press-release/coverage-at-work-the-share-of-nonelderly-americans-with-employer-based-insurance-rose-modestly-in-recent-years-but-has-declined-markedly-over-the-long-term/> (“job-based insurance remains the nation’s single largest source of coverage”).

113. Roberts, *supra* note 104, at 2023–24.

unable to work, will be entitled to Medicare coverage within two years of receiving the SSDI.¹¹⁴

Eligibility for Medicaid is determined by income and financial resources and thus is tied to SSI, a welfare program based on individuals' earnings in relation to the federal poverty level.¹¹⁵ As states administer the Medicaid program, eligibility for it varies. Some states that did not want to engage in the ACA's project of Medicaid expansion¹¹⁶ opted to use tighter eligibility standards than the federal criteria for Medicaid eligibility based on an older rule.¹¹⁷

The process of applying for Social Security benefits can be confusing and grueling for many. To be eligible for either SSI or SSDI, a claimant needs to prove he or she is disabled based on the Social Security Act's definition of disability. A wide conceptual gap exists between the definition of disability in the Social Security Act, which focuses on the inability to work,¹¹⁸ and the ADA's definition, which borrows at least to some extent from the social model of disability.¹¹⁹ As I have discussed

114. 42 U.S.C. § 426(b) (2021).

115. SSI is designed for low-income individuals who did not earn enough work credits before becoming disabled or turning sixty-five and therefore are not eligible for SSDI. *See* 42 U.S.C. § 1396a(a)(10)(A)(i)(II) (2021).

116. States have established tighter eligibility standards despite great efforts on the part of the Department of Health and Human Services to convince states that they should expand Medicaid in the wake of the *NFIB v. Sebelius* case which rendered such a move optional. *See* Nicole Huberfeld, *The Universality of Medicaid at Fifty*, 15 YALE J. HEALTH POL'Y L. & ETHICS 67, 78 (2015). On the social importance of Medicaid expansion, see generally Nicole Huberfeld & Jessica L. Roberts, *Medicaid Expansion as Completion of the Great Society*, 2014 ILLINOIS L. REV. SLIP. OP. 1, 3–5 (2014) (describing Medicaid's growth into a social insurance).

117. The rule is known as the "209(b) option" see 42 U.S.C. § 1396a(f) (2021). SSI was established in 1972 and replaced an older benefits program aimed at the Aged, Blind, and Disabled. As SSI expanded eligibility and increased the number of beneficiaries, the 209(b) option was enacted to allow states who wished to do so to keep their original, stricter, eligibility standards for Medicaid (from before 1972). "As of 2001, eleven states (Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, and Virginia) had elected the "209(b)" option to apply their 1972 eligibility criteria to aged or disabled individuals receiving SSI benefits for purposes of determining Medicaid eligibility." *See Total SSI Beneficiaries in 2019*, KFF, <https://www.kff.org/medicaid/state-indicator/total-ssi-beneficiaries/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D> (last visited Sept. 18, 2021).

118. To be eligible for either SSI or SSDI, a claimant must prove he or she are "unable to engage in any Substantial Gainful Activity, by a reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than twelve months." 42 U.S.C. § 423(d)(1)(A) (2021).

119. Doron Dorfman, *Re-Claiming Disability: Identity, Procedural Justice and the Disability Determination Process*, 42 LAW & SOC. INQUIRY 195, 204 (2017); Belt &

elsewhere, claimants often have trouble proving they fit under the Social Security Act's definition of disability because it may be counterintuitive for them to present themselves as unable to work because throughout their lives they were taught to prove their worth and "to put their best face forward."¹²⁰ Experiences of benefits' claimants also point to intrusive and scrutinizing questions and techniques used during the disability determination process to screen out claimants.¹²¹ And retaining the benefits, which are negligible,¹²² is often a struggle as well.¹²³

Under the current health-care insurance system, losing one's job¹²⁴ or public benefits also means losing one's health insurance. Therefore,

Dorfman, *supra* note 5, at 154 ("This [ADA] definition [of disability], therefore, has elements borrowed from the social model, as it recognizes the way disabling attitudes themselves can make someone deserving of protection against discrimination"); Arlene S. Kanter, *The Law: What's Disability Studies Got To Do With It Or An Introduction to Disability Legal Studies*, 42 COLUM. HUM. RTS. L. REV. 403, 427 (2011) ("The social model places the responsibility squarely on society . . . to remove the physical and attitudinal barriers that "disable" people with various impairments, and prevent them from exercising their rights and fully integrating into society.").

120. Dorfman, *supra* note 119, at 218.

121. See KATIE SAVIN, "BEING ON SSI IS A FULL-TIME JOB:" HOW SSI AND SSDI BENEFICIARIES WORK AROUND AND WITHIN LABOR INCENTIVE PROGRAMS 12 (2019), https://ardraw.policyresearchinc.org/wp-content/uploads/2019/07/Savin_ARDRAW-Report.pdf; Dorfman, *supra* note 119, at 218–20; Doron Dorfman, *Disability Identity in Conflict: Performativity in the U.S. Social Security Benefits System*, 38 T. JEFFERSON L. REV. 47, 67–68 (2015).

122. The amount of SSDI is determined by the beneficiaries' accumulated work credits and average indexed monthly earnings while they were working, see Social Security, *Primary Insurance Amounts*, SSA.GOV, <https://www.ssa.gov/OACT/COLA/Benefits.html> (last visited Sept. 19, 2021). In 2021, individual recipients of SSI receive up to \$794 a month and couples receive up to \$1,191 a month, see Social Security, *SSI Federal Payment Amount for 2021*, SSA.GOV, <https://www.ssa.gov/oact/cola/SSI.html> (last visited Sept. 19, 2021). Those negligible amounts lead beneficiaries to lives in poverty. Henry J. Whittle et. al., "The Land of the Sick and the Land of the Healthy": Disability, Bureaucracy, and Stigma Among People Living with Poverty and Chronic Illness in the United States, 190 SOC. SCI. & MED. 181, 186–87 (2017) (explaining that "in addition to these stigmas of disability, [research] participants also described experiencing stigmas of poverty Even when participants were routinely receiving [Social Security] disability benefits, however, monthly income was generally barely enough to cover basic living expenses Sometimes . . . this poverty was the result of bureaucratic delays in gaining access to cash assistance or having paychecks temporarily cut off, which could result in destitution.").

123. SAVIN, *supra* note 121, at 12 ("While for some participants the lack of certainty and consistency regarding SSD administration created constant concern, others – particularly those who had been receiving benefits for longer – seemed to have adapted with a more fatalistic and practical approach: "You report earnings and they screw you over and you don't report earning and they screw you over, so I just stopped . . . sure it's a worry, but it's not one I can do anything about.").

124. And the COVID-19 pandemic disproportionately affected people with disabilities in that respect as well, see Andy Newman, *I Really Loved My Job': Why the Pandemic Has Hit*

people with disabilities, who have greater health needs and thus require health insurance coverage often more than nondisabled individuals do,¹²⁵ will do what it takes to keep their jobs or benefits. For a person managing disabilities, losing one's income—and thus one's health insurance—can amount to a death sentence, as one court has noted.¹²⁶

More than a decade has passed since the ACA was enacted. While its effects on nondisabled and disabled Americans should be celebrated in terms of ensuring more affordable and accessible health insurance, approximately 10.9% of the population, or 28.9 million individuals, were still uninsured in 2019.¹²⁷ Most of those uninsured are lower income with at least one worker in the family (reflecting the more limited availability of insurance in states that did not expand Medicaid). People of color are also at higher risk of being uninsured.¹²⁸ The correlation between poverty, race, and disability renders people with disabilities to be members of this uninsured population.¹²⁹

The ACA, however, was never meant to be the end point, and in recent years the discourse around another reform that would ensure universal health care has arisen, especially among liberals/progressives.¹³⁰ Two options for such reform are on the table. The more ambitious one is Medicare for All, which guarantees coverage to all residents and is almost wholly dependent on federal funding from tax dollars (under such a program, neither the ACA nor Medicaid would exist). The second one is the public option or a public buy-in program that would offer a competitive public insurance plan alongside private insurance and would give the choice to individuals as to which to join

These Workers Harder, N.Y. TIMES (March 5, 2021), <https://www.nytimes.com/2021/03/05/nyregion/workers-disabilities-unemployment-covid.html>.

125. Bagenstos, *The Future of Disability Law*, *supra* note 100, at 27; Roberts, *supra* note 104, at 1990–91.

126. *Boatner v. Berryhill*, No. 3:16-cv-243-CWR-RHW, 2018 U.S. Dist. LEXIS 82570, at *24 (S.D. Miss., May 11, 2018) (“The injustices of the disability payment system are both many and deep. Research suggests the majority of denials may be incorrect, and applicants struggling to manage their disabilities say such denials can amount to a ‘death sentence.’”).

127. This is compared to 46.5 million uninsured in 2010, before the ACA. See Jennifer Tolbert, Kendel Orgera & Anthony Damico, *Key Facts About the Uninsured*, KFF (Nov. 6, 2020), <https://www.kff.org/uninsured/issue-brief/key-facts-about-the-uninsured-population/>.

128. *Id.*

129. Chin, *supra* note 9, at 690–91; Belt & Dorfman, *supra* note 5, at 152.

130. Blake, *supra* note 106, at 802–03.

(under such plans, Medicare and Medicaid would continue to exist).¹³¹ President Biden has expressed support for the public option plan.¹³²

The move to universal health care would finally remove the structural barriers existing in society and allow all people with disabilities to be fully included into society, as Bagenstos suggested in his 2004 article. Yet, as Martha Fineman and Ani Satz have argued, vulnerability to illness and the subsequent need for health-care coverage is not only a disability rights issue but also an essential aspect of the human condition.¹³³ Similar to Bagenstos, Satz also supports the idea of addressing health care outside of the antidiscrimination framework.¹³⁴ Jessica Roberts proposed an integrated approach that uses a “positive right” to health in conjunction with antidiscrimination protections. Roberts views the ACA with its antidiscrimination protections as an example of a statute that combines the best of both worlds.¹³⁵

An aspirational future of the ADA thus supports universal health care and would introduce a right to health care as a positive right within the statute itself. Though the ADA could be amended to declare such a right to health care, the implementation of such a right would be determined in other federal and state legislation that could refer back to the ADA's antidiscrimination mandates and create an integrated approach that views disability as both a social problem and yet “still a health issue.”¹³⁶

FINAL THOUGHTS

In her memoir, and in the critically acclaimed documentary “Crip Camp,”¹³⁷ disability rights champion and one of the participants in the symposium for this Special Volume, Judith Heumann, described her early experiences in a 1970s summer camp for disabled children:

131. *Id.* at 803–06.

132. Health Care, JOE BIDEN, <https://joebiden.com/healthcare/> (last visited Sept. 19, 2021) (“Giving Americans a new choice, a public health insurance option like Medicare”).

133. Martha Albertson Fineman, *The Vulnerable Subject: Anchoring Equality in the Human Condition*, 20 YALE J.L. & FEMINISM 1, 1 (2008) (arguing that “vulnerability is—and should be understood to be—universal and constant, inherent in the human condition”); Satz, *supra* note 99, at 561 (applying Fineman’s vulnerability theory within disability legal studies).

134. Satz, *supra* note 99, at 552.

135. Roberts, *supra* note 104, at 2032.

136. Tom Shakespeare, *Still a Health Issue*, 5 DISABILITY & HEALTH J. 129, 129, 131 (2012).

137. Directed, written, and co-produced by Nicole Newnham and James LeBrecht, CRIP CAMP (Higher Ground Productions 2020).

At camp we tasted freedom for the first time in our lives . . . The freedom we felt at camp was not just from our parents and our need for their daily assistance in order to live our lives. We were drunk on the freedom of not feeling like a burden, a feeling that was a constant companion in our lives outside of camp . . . Camp was for us. It was designed specifically with our needs in mind . . . Camp, I thought, was what it would feel like if society included us.¹³⁸

That 1970s summer camp, with its expressed values as well as aspects of the infrastructure and policies in place, should become the model for greater society. In this piece I articulated ambitious law reforms that would allow for a solid foundation from which disability justice could flourish. I elaborated on the need to secure emergency plans that embed the needs of individuals with disabilities, taking an active approach to promoting compliance with accessibility standards in built and online environments and securing the health needs of this population through universal health care. Law plays an important role in providing the groundwork for rich imagined futures described by Kafer.¹³⁹ The future of the ADA thus lies in adopting an integrated approach of positive rights alongside antidiscrimination mandates to make such vision a reality.

138. JUDITH HEUMANN & KRISTEN JOINER, BEING HEUMANN: AN UNREPENTANT MEMOIR OF A DISABILITY RIGHTS ACTIVIST 24–25, 27 (2020).

139. See *supra* notes 1–6 and accompanying text.