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Prisons, Nursing Homes, and Medicaid: A COVID-19 Case Study in Health Injustice

Mary Crossley[†]

Racial disparities in the pandemic

It didn't take long. Only weeks into the shutdown, forecasts began to emerge that COVID-19 would disproportionately affect Black communities. Dr. Uché Blackstock, a health equity expert, was sounding the alarm by late March 2020.¹ Soon after, reports of excess morbidity—to use the sterile language of epidemiology—were followed by reports of excess mortality among Black people. Put plainly, more Black people than white people were getting sick and dying of COVID-19.

Reports came from far and wide. At first it was the big cities. In Milwaukee, data reported in early April showed Black people making up nearly half of the coronavirus infections and 81% of deaths, even though they made up only 26% of the population.² A few days later, a report from Chicago shared that 70% of its deaths were of Black residents, though only 29% of the city's living residents were Black.³ Nor were Southern cities immune. In New Orleans, which celebrated Mardi Gras just as the virus was gaining a foothold, deaths in the predominantly Black Orleans Parish accounted for 40% of the deaths in the entire state of Louisiana. We also started hearing about “super spreader” events in Black communities in smaller locales. A funeral in Albany,

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¹ Julia Craven, *How Racial Health Disparities Will Play Out in the Pandemic*, SLATE, Mar. 30, 2020, <https://slate.com/news-and-politics/2020/03/how-racial-health-disparities-will-play-out-in-the-coronavirus-pandemic.html> (interviewing Dr. Blackstock); see also Ibram X. Kendi, *What the Racial Data Show: The Pandemic Seems to be Hitting People of Color the Hardest*, THE ATLANTIC, Apr. 6, 2020, <https://www.theatlantic.com/ideas/archive/2020/04/coronavirus-exposing-our-racial-divides/609526/>.

² Akilah Johnson & Talia Buford, *Early Data Shows African Americans Have Contracted and Died of Coronavirus at an Alarming Rate*, PROPUBLICA, Apr. 3, 2020, <https://www.propublica.org/article/early-data-shows-african-americans-have-contracted-and-died-of-coronavirus-at-an-alarming-rate>.

³ Elliott Ramos & Maria Ines Zamudio, *In Chicago, 70% of COVID-19 Deaths are Black*, WBEZ, April 5, 2020, <https://www.wbez.org/stories/in-chicago-70-of-covid-19-deaths-are-black/dd3f295f-445e-4e38-b37f-a1503782b507>.

Georgia left the midsize city's sole hospital overwhelmed by patients suffering from an illness that its doctors had never seen before.⁴

The story line that emerged early in the pandemic has persisted: COVID-19 has been hitting Black and brown Americans especially hard. The steady drumbeat of reporting about those racial disparities grew numbing. But for folks familiar with the pervasiveness and persistence of racial health disparities prior to the pandemic, the reports were not surprising. Dr. Camara Jones, a family physician and former president of the American Public Health Association, reflected: "COVID is just unmasking the deep disinvestment in our communities, the historical injustices and the impact of residential segregation."⁵ The predictability of the disparities did not detract from their devastating impact.⁶

More focused reports told stories with a finer grain. Black Medicare beneficiaries were hospitalized with COVID-19 at rates nearly quadruple those of their white counterparts.⁷ At the opposite end of the age spectrum, Black children infected with the virus were five times more likely to need hospitalization than white children.⁸ Predominantly Black and Latino neighborhoods in New York City suffered death rates as much as fifteen times higher than those experienced in

⁴ Haisten Willis & Vanessa Williams, *A Funeral is Thought to have Sparked a Covid-19 Outbreak in Albany, Ga., -- and Led to Many More Funerals*, WASH. POST, April 4, 2020, https://www.washingtonpost.com/politics/a-funeral-sparked-a-covid-19-outbreak--and-led-to-many-more-funerals/2020/04/03/546fa0cc-74e6-11ea-87da-77a8136c1a6d_story.html.

⁵ Johnson & Buford, *supra*

⁶ Richard A. Opiel, Jr. et al, *The Fullest Look Yet at the Racial Inequity of Coronavirus*, N.Y. TIMES, July 5, 2020, <https://www.nytimes.com/interactive/2020/07/05/us/coronavirus-latinos-african-americans-cdc-data.html>.

⁷ Maria Godoy, *Black Medicare Patients with COVID-19 Nearly 4 Times as Likely to End up in Hospital*, NPR, June 22, 2020, <https://www.npr.org/sections/health-shots/2020/06/22/881886733/black-medicare-patients-with-covid-19-nearly-4-times-as-likely-to-end-up-in-hosp#:~:text=New%20federal%20data%20reinforces%20the,higher%20than%20their%20white%20counterparts>.

⁸ Chelsea Janes, *Hispanic, Black children at higher risk of coronavirus-related hospitalization, CDC finds*, WASH. POST, Aug. 7, 2020, <https://www.washingtonpost.com/health/2020/08/07/hispanic-black-children-higher-risk-coronavirus-related-hospitalization-cdc-finds/>. The disparity was even greater for Hispanic children, whose hospitalization rates were eight times those of white children.

predominantly white neighborhoods a subway ride away.⁹ And the racial disparities in patient experiences and outcomes translated into disproportionately severe physical and mental health risks for Black health care workers.¹⁰ If there were any “bright spots,” where Black people were not suffering more from the pandemic than white Americans, I sure didn’t hear about them.

As data piled up showing that Black people in the U.S. were disproportionately getting sick and dying from COVID-19, many recognized that the pandemic was simply laying bare the disparities that have long pervaded our society and health care system. More critically, some have pointed out that factors contributing to the disparate doling out of disease and death result from choices we have made as a society. Legal scholar Kimberlé Williams Crenshaw wrote of “people of color whose chances of survival [from COVID-19] were handicapped by generations of human-engineered disasters before they found themselves in the path of a natural one.”¹¹

The point bears emphasizing: Biology does not explain these disparities. Or as Patricia Williams put it, race is not “a signifier of innate disease propensity.”¹² Social, economic, and environmental pathologies—rather than genetic variants—explain the disparities. Here’s a partial listing of explanations. Essential workers (as the term has come to be used during the pandemic), whose work requires contact with the public, include many Black people. Enjoying fewer economic resources than white people (as the result of a history of overt discrimination and continuing structural racism), Black people and other people of color are more likely to live in

⁹ Maria Caspani & Jonathan Allen, Coronavirus Deadliest in New York City’s black and Latino neighborhoods, data show, Reuters, May 18, 2020, <https://www.reuters.com/article/us-health-coronavirus-new-york-deaths/coronavirus-deadliest-in-new-york-citys-black-and-latino-neighborhoods-data-shows-idUSKBN22U32A>.

¹⁰ Adia Harvey Wingfield, *The Disproportionate Impact of Covid-19 on Black Health Care Workers in the U.S.*, HARV. BUS. REV., May 14, 2020, <https://hbr.org/2020/05/the-disproportionate-impact-of-covid-19-on-black-health-care-workers-in-the-u-s>

¹¹ Kimberle Williams Crenshaw, *When Blackness is a Preexisting Condition*, THE NEW REPUBLIC, May 4, 2020, <https://newrepublic.com/article/157537/blackness-preexisting-condition-coronavirus-katrina-disaster-relief>.

¹² Patricia J. Williams, *The Endless Looping of Public Health and Scientific Racism*, in *Assessing Legal Responses to COVID-19*, [source] at 267, Aug. 2020, www.covid19policyplaybook.org.

crowded housing and use public transportation, making it more difficult to use social distancing to prevent infection.¹³ Reflecting long-standing health disparities that pre-dated the pandemic, Black people suffer from higher rates of chronic health conditions like hypertension, chronic lung diseases, obesity, and diabetes, all of which increase the risk that a COVID-19 infection will be severe or deadly.¹⁴ These disproportionate prevalences are traceable to social determinants of health like poverty, food insecurity, environmental toxins, and stress, to name just several. In addition, Black people had higher rates of being uninsured (apparently employers of “essential” workers don’t always view their labors as meriting health coverage) and faced more numerous barriers to accessing high quality medical care.¹⁵ To top it off, a long history of racism within medicine and public health has fed a reservoir of mistrust in Black communities, especially when it comes to new and deadly diseases.¹⁶ Before the pandemic, these factors were part of the background of daily existence. In the pandemic, they have combined to produce greater burdens of COVID-19 illness and death.

Whether one points to employment in “essential” service jobs, a greater likelihood of living in densely packed housing, or higher rates of underlying health conditions, all these explanations for COVID-19’s disproportionate impact on Black people reflect social or political choices, either directly or indirectly. Sociologist Courtney Boen, whose work focuses on health inequality, puts it succinctly: “These are not natural or inevitable biological consequences. . . . Any disparity that

¹³ Jennifer Abbasi, *Taking a Closer Look at COVID-19, Health Inequities, and Racism*, 324 JAMA 427 (2020).

¹⁴ Monica Webb Hooper, Anna Maria Napoles & Eliseo J. Perez-Stable, *COVID-19 and Racial/Ethnic Disparities*, 323 JAMA 2466 (2020).

¹⁵ *Id.*

¹⁶ Jason Breslow, *Why Misinformation and Distrust are Making COVID-19 More Dangerous for Black America*, NPR, Apr. 10, 2020, <https://www.npr.org/sections/coronavirus-live-updates/2020/04/10/832039813/why-misinformation-and-distrust-is-making-covid-19-more-dangerous-for-black-america>.

we're seeing in terms of race in the pandemic is socially and politically constructed. These disparities are due to racism.”¹⁷

Disability disparities in the pandemic

People with disabilities also have faced heightened peril and suffered a disproportionate toll during the pandemic. We know less about COVID-19 infection rates and deaths of people with disabilities because that data has not been systematically collected and reported in the U.S.¹⁸ Some evidence, however, is available, for example the tally of deaths in nursing homes. As of November 15, 2020, nearly 70,000 nursing home residents—most of whom we can presume were disabled—had died from COVID-19.¹⁹ The virus also has disproportionately infected disabled people living in group homes. Early research indicates that people with developmental disabilities who live in group homes are four times as likely as the general population to contract COVID-19 and about twice as likely to die from it.²⁰

¹⁷ Sidnee King & Joel Jacobs, *Near birthplace of Martin Luther King Jr., a predominantly Black nursing home tries to heal after outbreak*, WASH. POST, Sept. 9, 2020, <https://www.washingtonpost.com/business/2020/09/09/black-nursing-homes-coronavirus/>.

¹⁸ Nicholas S. Reed, et al., *Disability And Covid-19: Who Counts Depends On Who Is Counted*, 5 *The Lancet Public Health* 423 (2020). DOI: [https://doi.org/10.1016/S2468-2667\(20\)30161-4](https://doi.org/10.1016/S2468-2667(20)30161-4).

¹⁹ COVID-19 Nursing Home Data, Data.CMS.gov, <https://data.cms.gov/stories/s/COVID-19-Nursing-Home-Data/bkwz-xpvg/>. This number is smaller than the 100,000 deaths reported in late November 2020; the larger number included deaths of both long-term care facility residents and staff. Priya Chidambaram, Rachel Garfield & Tricia Neuman, *COVID-19 has Claimed the Lives of 100,00 Long-term Care Residents and Staff*, Kaiser Family Foundation, Nov. 25, 2020, <https://www.kff.org/policy-watch/covid-19-has-claimed-the-lives-of-100000-long-term-care-residents-and-staff/>. That 100,000 deaths represents approximately 20% of the total U.S. coronavirus deaths recorded by late November 2020. Note distinction from percentage reports of deaths related to nursing homes, which includes both residents and staff. As discussed further below, many people in nursing homes stay there only briefly as they recover from an illness or injury requiring hospital treatment, long-term stays are virtually all by people who require assistance with daily living as the result of disabling conditions. [data re %age of Rez in S-T post acute stays?] At any given time, a large proportion of nursing home residents are long-term residents. Thus, a high percentage of the nursing home residents who have died from COVID can be presumed to be people with disabilities.

²⁰ Joseph Shapiro, *COVID-19 Infections and Deaths are Higher Among Those with Intellectual Disabilities*, NPR, June 9, 2020, <https://www.npr.org/2020/06/09/872401607/covid-19-infections-and-deaths-are-higher-among-those-with-intellectual-disabili>; Research from the United Kingdom regarding adults with Down syndrome found even greater disparities in rates of hospitalization and deaths. Mary Van Beusekom, *Down syndrome tied to 10 times the*

Disparities are not limited to congregate living settings. According to the CDC, more than nine in ten people who died from COVID-19 also had some other health condition that contributed to their death.²¹ Although definitions of disability vary (in both legal and nonlegal contexts), conditions like diabetes, heart disease, and asthma can all constitute disabilities.²² In December 2020, the CDC added Down syndrome to its list of conditions that place patients at risk for severe COVID.²³ Data from the British Office of National Statistics further demonstrates the disproportionate impact on disabled people. In September 2020, that office reported that 59% of all deaths in England and Wales from March 2 to July 14 were of disabled people.²⁴

From early in the pandemic, disabled people sounded the alarm about the existential threat the virus posed to many in their ranks.²⁵ The fear is that discrimination—operating under the guise of triage policies or “crisis standards of care”—would result in people with disabilities being deprived of needed medical care and supports, with potentially deadly consequences. In early April, Alice Wong, a disabled activist, media maker, and consultant who uses a power wheelchair and non-invasive ventilator, wrote:

risk of COVID-19 death, CIDRAP, Oct. 22, 2020, <https://www.cidrap.umn.edu/news-perspective/2020/10/down-syndrome-tied-10-times-risk-covid-19-death>

²¹ Travis Andersen, *CDC says most COVID-19 death in US involved underlying health conditions*, BOSTON GLOBE, Aug. 31, 2020, <https://www.bostonglobe.com/2020/08/31/metro/cdc-most-covid-19-deaths-us-involved-underlying-health-conditions/>

²² The conditions fall within the ADA’s definition of disability if they have the effect of limiting a person’s major life activities. [cite to source re ADA, and re commentator making point that these underlying health condition = DA]

²³ Zachary Mack, *The DCD Just Confrimed This Disorder Could Put You at Risk of Severe COVID*, BestLife, Jan. 1, 2021, <https://bestlifeonline.com/cdc-down-syndrome-covid/>.

²⁴ *Coronavirus (COVID-19) related deaths by disability status, England and Wales: 2 March to 14 July 2020*, OFFICE FOR NAT’L STATISTICS, Sept. 18, 2020, <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/2marchto14july2020>. The report counted people as disabled if they reported that their daily activities were limited a little or limited a lot by disability or a health problem.

²⁵ Abigail Abrams, *‘This is Really Life or Death.’ For People with Disabilities, Coronavirus is Making it Harder than ever to Receive Care*, TIME, Apr. 24, 2020, <https://time.com/5826098/coronavirus-people-with-disabilities/>; Elaine Godfrey, *Americans with Disabilities are Terrified*, THE ATLANTIC, Apr. 3, 2020, <https://www.theatlantic.com/politics/archive/2020/04/people-disabilities-worry-they-wont-get-treatment/609355/>.

Were I to contract coronavirus, I imagine a doctor might read my chart, look at me, and think I'm a waste of their efforts and precious resources He might even take my ventilator for other patients who have a better shot at survival than me. All of these hard choices doctors have to make primarily hurt those hit hardest, not the people who present as worthy investments of scarce resources. Who gets to make these hard choices and who bears the brunt of them is a matter of inequality and discrimination toward protected classes.²⁶

The unevenly distributed pain and suffering from the pandemic present a remarkable case study. References to “structural discrimination” or “institutional racism” can seem abstruse. But considering why the coronavirus has devastated some groups more than others offers a concrete example of those abstract concepts, an example measured in lives lost, families shattered, and unremitting anxiety. This essay highlights the experiences of Black people and disabled people, and how societal choices have caused them to experience the brunt of the pandemic. It will focus on prisons and nursing homes—institutions that emerged as COVID-19 hotspots —and on the Medicaid program.

Black and disabled people are disproportionately represented in prisons and jails. Nursing homes and other care facilities are full of people who need care or assistance because of physical or mental disabilities. It's no accident that so many Black and disabled people are incarcerated and so many disabled people are in nursing homes or other institutions. These realities do not reflect some criminological or biological inevitability. Instead, who ends up in these pandemic hotspots reflects choices our society has made and the value we've placed on human lives. The disparate effects are traceable to political and policy decisions—from racially tinged political decisions to pursue a “war on drugs,” to states' halting progress in increasing the availability of home and community-based services (HCBS) for people with disabilities, to the decisions by a dozen states

²⁶ Alice Wong, *I'm disabled and need a ventilator to live. Am I expendable during this pandemic?*, VOX, Apr. 4, 2020, <https://www.vox.com/first-person/2020/4/4/21204261/coronavirus-covid-19-disabled-people-disabilities-triage> ; see also note ____.

to reject federal funding for covering more low-income residents. When we look closely, the virus's rampage through institutions and communities reveals the truth that politics, not biology, determines who is especially vulnerable to poor health and premature death. In arguing for a "civil rights of health" initiative, Angela Harris and Aysha Pamukcu put it simply: "Vulnerability is made, not born."²⁷

In addition, high rates of illness and death among people with disabilities and Black people are not unconnected. Although some variability exists by disability type, disability is generally more prevalent among Black Americans than among whites, Latinos, and Asians.²⁸ This intersection of race and disability is under-studied, but extant research does not point to innate biological differences as an explanation. Instead, the higher prevalence of disability among Black Americans reflects an increased likelihood of developing or acquiring disability through social and environmental causes. Negative attitudes towards and devaluation of the lives of Black people and disabled people are connected as well. As Harriet Williamson writes: "Ableism wraps into other prejudices."²⁹

This essay explores how the pandemic illuminates structural discrimination against Black people and disabled people by considering how the vulnerability of those groups has been made. It presents an array of choices—some stretching back decades and others more recent—that led to disproportionate representation of Black people and people with disabilities in both nursing homes (particularly those hardest hit by COVID-19) and in prisons and jails. In so doing it will highlight

²⁷ Angela P. Harris & Aysha Pamukcu, *The Civil Rights of Health: A New Approach to Challenging Structural Inequality*, 67 UCLA L. REV. 758 (2020).

²⁸ SILVIA YEE ET AL., COMPOUNDED DISPARITIES: HEALTH EQUITY AT THE INTERSECTION OF DISABILITY, RACE, AND ETHNICITY 10–19 (2016).

²⁹ Williamson, *supra* note _____. As an example, Williamson points to HHS Secretary Alex Azar's remarks that "America 'unfortunately' has a 'very diverse' population and Black Americans and minorities 'in particular' have 'significant underlying disease.' Azar was essentially blaming people of color for their own deaths because he deems them to be unhealthy."

the importance of intersectionality of race and disability in these COVID-19 hotspots. The essay will also review how decisions regarding the Medicaid program, particularly some states' choice not to expand Medicaid pursuant to the Affordable Care Act (ACA), have contributed to disparities in the burden of COVID-19 illness and death. Although the essay's primary emphasis is on these "rearview mirror" choices, it will conclude by briefly suggesting how going-forward choices made during the pandemic implicate health justice. Keeping equity issues centered will be critical to pursuing policies that mitigate, rather than further entrench unjust health disparities.

Infection and Incarceration

Prisons and jails are prime territory for COVID-19 outbreaks. As of October 2, 2020, these institutions accounted for all of the seventeen largest clusters of COVID-19 cases anywhere, with more than twenty of those institutions reporting more than 1,000 cases apiece, according to data collected by the *New York Times*.³⁰ Among other factors, the persons confined typically are tightly crowded together and have limited access to Personal Protective Equipment (PPE). Social distancing is challenging, if not impossible. Half of all incarcerated persons have one or more chronic diseases, like the cardiac and respiratory conditions that increase COVID-19 risks.³¹

One analysis of publicly available data through early June 2020 found that the COVID-19 case rate for persons in American prisons was 5.5 times higher than the case rate in the general population. Death rates were higher as well, and adjusting the data to reflect that prisons house a lower proportion of people aged sixty-five or older revealed a death rate three times higher in the prison population than in the general population.³²

³⁰ *COVID in the U.S.: Latest Map and Case Count*, N.Y. TIMES, Oct. 1, 2020, <https://www.nytimes.com/interactive/2020/us/coronavirus-us-cases.html#hotspots>.

³¹ Matthew J. Akiyama, Anne C. Spaulding & Josiah D. Rich, *Flattening the Curve for Incarcerated Populations*, 382 NEW ENG. J. MED. 2075, 2076 (2020).

³² Brendan Saloner et al., *Letter, COVID-19 Cases and Deaths in Federal and State Prisons*, 324 JAMA 602 (2020).

Interrogating why so many people confined to prisons and jails have contracted COVID-19 requires attention to choices that lie behind several related phenomena. The U.S. imprisons more of its citizens than any other country. *Why?* American prisons and jails inflict numerous serious health harms on the persons confined to them. *Why?* The Americans confined to prisons and jails in the U.S. are disproportionately Black, brown, and disabled. *Why?* Even a brief examination of these questions proves illuminating and disturbing.

It was not always the case that the United States led the world in incarcerating its citizens. The country's incarceration rate shot up starting in the 1980s, increasing 222 percent between 1980 and 2012.³³ As of 2020, 20% of all incarcerated persons were imprisoned in the U.S., which was home to only 5% of the world's population.³⁴

Both Black people and disabled people are incarcerated at rates exceeding their share of the population. In 2018, Black Americans represented 33% of the sentenced prison population, nearly triple their 12% share of the U.S. adult population.³⁵ A 2016 report found that persons incarcerated in prisons report having a disability at three times the rate of the general population.³⁶ The disproportion was even greater for people with cognitive disabilities or mental illness. Prison inmates were four times as likely as someone in the general population to have a cognitive disability; jail inmates were more than six times as likely. People with mental illness are similarly overrepresented, with one in five prison inmates suffering a serious mental illness³⁷ Mass

³³ Incarceration Rate in the United States, 1960-2012, The Hamilton Project, May 1, 2014, https://www.hamiltonproject.org/charts/incarceration_rate_in_the_united_states_1960-2012.

³⁴ Jessica Bresler & Leo Beletsky, *COVID-19, Incarceration, and the Criminal Legal System*, in *Assessing Legal Responses to COVID-19*, at ___ Aug. 2020, www.covid19policyplaybook.org.

³⁵ Whites accounted for 30% of prisoners, about half their 63% share of the adult population. Hispanics accounted for 23% of inmates, compared with 16% of the adult population. According to Pew Research Center, gaps in incarceration have narrowed somewhat over time. <https://www.pewresearch.org/fact-tank/2020/05/06/share-of-black-white-hispanic-americans-in-prison-2018-vs-2006/>.

³⁶ Rebecca Vallas, *Disabled behind Bars: The Mass Incarceration of People with Disabilities*, Center for American Progress, 1-2 (July 2016).

³⁷ *Id.*

incarceration is often described as a problem of disproportionately locking up Black and brown bodies, but critical disability scholars argue that the intersection of race, class, and disability more accurately describes the bodies subjected to the practice.³⁸ As one group of researcher/activists writing about the harms inflicted by the prison-industrial complex put it, “it is no mistake that poor disabled racialized bodies fill these spaces.”³⁹

Among the complex causes of high incarceration rates, one point bears particular attention. In the final third of the twentieth century, a swelling chorus of “tough on crime” rhetoric coincided with a dwindling political appetite for investing in social spending, particularly in communities where poverty was concentrated. Declining investment in human capital and resources for social supports in poor neighborhoods plagued by underfunded schools, addiction, and desperation went hand in hand with expanding roles for police and the criminal justice system in addressing social issues ranging from substance abuse, to mental health crises, to school discipline.⁴⁰

In *The New Jim Crow: Mass Incarceration in the Age of Colorblindness*,⁴¹ Michelle Alexander argues that the American criminal justice system operates across levels as a system of racial control akin to the Jim Crow regime. She describes how pursuit of the “War on Drugs” and the disparate enforcement of drug laws in urban neighborhoods have led to the striking racial disproportion in incarceration in the U.S. This “war” has cast Black and brown Americans living

³⁸ Nirmala Erevelles, *Crippin’ Jim Crow: Disability, Dis-Location, and the School-to-Prison Pipeline* 86, in *DISABILITY INCARCERATED: IMPRISONMENT AND DISABILITY IN THE UNITED STATES AND CANADA* (Liat Ben-Moshe et al. eds. 2014). In related work, Michael Rembis expands the discourse regarding incarceration from a focus on race and poverty to interrogate the connection between madness and incarceration. Michael Rembis, *The New Asylums: Madness and Mass Incarceration in the Neoliberal Era*, in *DISABILITY INCARCERATED: IMPRISONMENT AND DISABILITY IN THE UNITED STATES AND CANADA* 139 (Liat Ben-Moshe et al. eds. 2014).

³⁹ Syrus Ware et al., *It Can’t be Fixed because it’s not Broken: Racism and Disability in the Prison Industrial Complex* 178, in *DISABILITY INCARCERATED: IMPRISONMENT AND DISABILITY IN THE UNITED STATES AND CANADA* (Liat Ben-Moshe et al. eds. 2014).

⁴⁰ Worth noting is that disinvestment did not produce equally negative returns across racial lines, as the prison-building boom in rural America that accompanied rising incarceration rates produced stable employment for low-income white residents. See Rebecca Thorpe, *Urban Divestment, Rural Decline and the Politics of Mass Incarceration*, 23 *GOOD SOC’Y* 17 (2014).

⁴¹ MICHELLE ALEXANDER, *THE NEW JIM CROW: MASS INCARCERATION IN THE AGE OF COLORBLINDNESS* (2010).

in communities starved of resources as enemies to be vanquished, with entire neighborhoods suffering the collateral damage.⁴²

Disinvestment decisions also shed light on high rates of incarcerated people with disabilities. In the mid-twentieth century, states began closing mental hospitals and other institutions. Deinstitutionalization had a humane purpose: permitting people with disabilities to live in the community, rather than being confined to institutions. But states chose not to invest in community-based support systems and living alternatives for disabled people. Without those supports, significant numbers of disabled people faced difficulties managing their lives and became needlessly (but predictably) entangled in the criminal justice system. Critical scholars use the term “trans-institutionalization”⁴³ to refer to this process, where disabled people went from being confined in state mental hospitals and other institutions to being confined in jails and prisons. This shift in the locus of confinement appears in the numbers; three times as many people with mental health conditions now live in jails and prisons as reside in state mental hospitals. The continuation and relocation of confinement was not inevitable, however. Instead, it resulted from choices that devalued the lives and dignity of people with disabilities, from judgments that their independence and ability to contribute to society were not worthy of investment.

Criminal justice involvement is especially prevalent among people with cognitive disabilities like autism, learning disorders, Down syndrome, or dementia.⁴⁴ Legal scholar Jamelia Morgan describes how the lack of investment in community mental health, affordable housing, and social supports have created conditions ripe for discriminatory policing directed against

⁴² Lisa D. Moore & Amy Elkavich, *Who's Using and Who's Doing Time: Incarceration, the War on Drugs, and Public Health*, 98 AM. J. PUB. HEALTH 782 (2008).

⁴³ See, e.g., Laura I. Appleman, *Deviancy, Dependency, and Disability: The Forgotten History of Eugenics and Mass Incarceration*, 68 DUKE L.J. 417 (2018).

⁴⁴ Prison inmates are four times as likely as someone in the general population to have a cognitive disability; jail inmates are more than six times as likely. People with mental illness are similarly overrepresented. According to the Bureau of Justice Statistics, 20% of prison inmates have a serious mental illness. Vallas, *supra* note __, at 1–2.

disabled people.⁴⁵ This pattern is found in arrests of people with disabilities—particularly those experiencing some form of mental distress—for order maintenance or “quality of life” offenses like disorderly conduct, loitering, or nuisance. These arrests occur in public spaces, as well as in hospitals, the very sites where people go to seek treatment for their distress. They reflect an over-criminalization of conduct that is not in fact threatening, but that is deemed offensive because it makes non-disabled people feel uncomfortable. This “mental distress-to-arrest pipeline” leads to people landing in jail as a result of how their disability manifests.⁴⁶ Morgan sums up her thinking: “Where certain outward manifestations of disability are viewed as social problem, pathology, danger, or threat, society will respond to disability with punitive measures, whether through managing disability through aggressive policing or incapacitating disability in prisons and jails. This is true even where those behaviors may directly link to disability.”⁴⁷

And prison life itself may create disability in persons who had no disability prior to incarceration. Limited access to health care, inadequate nutrition, and high levels of violence can all contribute to physical disablement.⁴⁸ Punitive segregation and isolation can lead to trauma and the development of disabling mental health conditions. Indeed, the stresses and adverse conditions of life behind bars contributes to accelerated aging, with many corrections systems classifying prisoners as elderly beginning at the age of fifty or fifty-five.⁴⁹

In short, even before COVID-19’s arrival, health conditions in prisons and jails were commonly atrocious, with incarcerated persons subjected to overcrowding, inadequate sanitation, limited access to poor quality health care, pervasive violence, and chronic stress. Despite a legal

⁴⁵ Jamelia Morgan, *Policing Under Disability Law*, 73 STAN. L. REV. ____ (forthcoming 2021), draft at 7.

⁴⁶ Morgan, *supra* note ____, at 11–21.

⁴⁷ Morgan, *supra* note ____, at 8.

⁴⁸ Vallas, *supra* note ____, at 10–11.

⁴⁹ Human Rights Watch, *Old Behind Bars: The Aging Prison Population in the United States*, Jan. 27, 2012, https://www.hrw.org/report/2012/01/27/old-behind-bars/aging-prison-population-united-states#_ftn2.

obligation to provide medical care to persons they incarcerate, states' records have been spotty at best, with wide variability between states. These poor conditions are not always the product of a simple lack of resources. Rather, in many cases they reflect a choice to abdicate public responsibility and divert resources to prison health care companies, whose profit motive conflicts with prisoners' interest in receiving timely and quality care. A majority of states contract with private companies to supply some portion of their prison health care, and more than two-thirds of jails rely on private companies to provide medical services.⁵⁰ This reliance left correctional institutions ill equipped to respond to the pandemic.

This brief examination shows that it is no accident either that prisons and jails are disproportionately populated by Black people and people with disabilities or that those sites have experienced excessive rates of COVID-19.

*Nursing Homes: "Designed to fail years before Covid-19"*⁵¹

The narrative regarding nursing homes' emergence as pandemic hot spots is strikingly similar story. The first COVID-19 outbreak in the U.S. occurred in a nursing home in Kirkland, Washington, foreshadowing what lay ahead. Just a few months later, more than 153,000 nursing home residents and workers had been infected, and nursing homes accounted for 35% of the

⁵⁰ Steve Coll, *The Jail Health-Care Crisis*, THE NEW YORKER, Feb. 25, 2019. The increased reliance of for-profit companies to run prisons and jails comprehensively similarly figures into the full range of factors that make carceral environments unhealthy.

⁵¹ E. Tammy Kim, *This is Why Nursing Homes Failed so Badly*, N.Y. TIMES, Dec.31, 2020, <https://www.nytimes.com/2020/12/31/opinion/sunday/covid-nursing-homes.html>.

country's COVID-19 deaths.⁵² By June 2020, 45% of deaths nationally were linked to nursing facilities; in about half the states, a majority of fatalities were attributable to the facilities.⁵³

No one should have been surprised. Many of the reasons that persons confined to prisons and jails are so vulnerable to COVID-19 transmission have analogs in the nursing home world. Indeed, critical scholars at least since Foucault have described medical institutions like psychiatric hospitals and nursing homes as carceral in nature for serving to separate deviant bodies from dominant society.⁵⁴ Considered individually, most residents of nursing homes are in a high-risk category for COVID-19 by virtue of their health conditions or their age (or both). These high-risk individuals live in congregate settings and must come into close contact with the staff who provide care (and who disproportionately come from low-income communities of color that have suffered disproportionately high infection rates). Staff are typically paid such low wages that some are forced to work in multiple facilities to make ends meet; doing so, though, may contribute the virus's spread from facility to facility. And, similar to prisons, for-profit chains focused on cost cutting increasingly dominate the nursing home industry.⁵⁵ One trio of commentators described nursing homes as "like tinderboxes, ready to go up in flames with just a spark."⁵⁶ They attributed this condition to "decades of neglect of long-term care policy."⁵⁷ That assertion is justified, but the neglect has harmed some groups more than others. As with prisons and jails, policy choices

⁵² Rachel M. Werner, Allison K. Hoffman & Norma B. Coe, *Long-Term Care Policy after COVID-19—Solving the Nursing Home Crisis*, 383 NEW ENG. J. MED. 903 (2020).

⁵³ Statement of Eric Carlson to House Select Subcommittee on the Coronavirus Crisis, June 11, 2020, <https://coronavirus.house.gov/sites/democrats.coronavirus.house.gov/files/2020.06.11%20Eric%20Carlson%20-%20Testimony.pdf>.

⁵⁴ See Allison C. Carey, Liat Ben-Moshe & Chris Chapman, Preface: *An Overview of Disability Incarcerated*, in *DISABILITY INCARCERATED: IMPRISONMENT AND DISABILITY IN THE UNITED STATES AND CANADA* ix-xi (Liat Ben-Moshe et al. eds. 2014).

⁵⁵ Kim, *supra* note ____.

⁵⁶ Werner et al., *supra* note ____.

⁵⁷ Werner et al., *supra* note ____.

regarding nursing homes -- while perhaps not discriminatory on their faces – have produced a negative impact from COVID-19 for disabled people and Black people.

The common conception of nursing homes residents is of elderly frail persons. Younger, more robust people often devalue the life remaining for nursing home residents. Texas Lieutenant Governor Dan Patrick’s comment, made early in the pandemic, that older Americans should accept the risk of infection and death in order to permit the economy to function without interruption⁵⁸ exhibits this ageism, which tends to be particularly acute for people compelled to live in nursing homes. The devaluation shows up starkly in the difficulty of suing nursing homes because tort law attaches so little financial value to an injured resident’s life. It also appears in state and federal regulators’ failure to exercise rigorous oversight of safety practices at nursing homes, discussed below.

But while many nursing home residents are elderly, a significant fraction are minors or non-elderly adults.⁵⁹ The common denominator for most nursing home residents is that they are somehow disabled.⁶⁰ Thus, nursing homes’ catastrophically high rates of COVID-19 illness and death are primarily affecting disabled people, a reality often obscured by depictions of residents simply as old. Moreover, people of color residing in nursing homes are also suffering more grievously. Nursing homes with higher percentages of Black and Latino patients are more likely

⁵⁸ Texas Lt. Gov. Dan Patrick suggests he, other seniors willing to die to get economy going again, Mar. 24, 2020, <https://www.nbcnews.com/news/us-news/texas-lt-gov-dan-patrick-suggests-he-other-seniors-willing-n1167341>.

⁵⁹ Ashley Cleek, *Young, disabled and stuck in a nursing home for the elderly*, AL JAZEERA ENGLISH, Oct. 2, 2013, <http://america.aljazeera.com/articles/2013/10/2/young-disabled-andstuckinnursinghomes.html> (reporting CMS figures that one out of seven residents in nursing homes were under the age of sixty-five and that the number of younger residents was growing). Elaine K. Howley, *Nursing Home Facts and Statistics*, U.S. NEWS HEALTH, Nov. 2, 2020, <https://health.usnews.com/health-news/best-nursing-homes/articles/nursing-home-facts-and-statistics#expert-sources> (citing 2015–16 data from the National Center for Health Statistics that 16.5% of nursing home residents were younger than 65).

⁶⁰ To be sure, some number of persons receiving care in nursing homes on any given day do not have a long-term disability, but are there temporarily while recovering from an acute illness, surgery, or accident. The longer-term residents of nursing homes, by contrast, are people who are somehow disabled, perhaps as the result of aging but not necessarily.

to report at least one coronavirus case. And the larger the percentage of Black patients residing in a nursing home, the higher the death rate from COVID-19.⁶¹ A large analysis of reported COVID-19 deaths in nursing homes, using data available through the beginning of September 2020, found that in majority-Black nursing homes the death rate from COVID-19 was more than 20% higher than in majority-white facilities. And the disparity grew as the proportion of Black residents increased, with homes having at least 70% Black residents reporting death rates about 40% higher than in facilities with mostly white residents.⁶²

Again, we have to ask why. The devastating rates of illness and death afflicting disabled people and Black people residing in nursing homes are not coincidental. Nursing home patients are “victims not just of density but of a broader societal disregard toward older people and those with disabilities.”⁶³ In addition, as discussed below, the failure to enforce civil rights laws and safety regulations against nursing homes has permitted significant racial segregation, with people of color more likely to reside in facilities with the most serious quality problems.

The starting point for understanding why so many disabled people live in institutional settings prone to contagion is that many of them reside in nursing homes, not because they wish to or because they need an institutional level of care, but instead because of insufficient state funding for home and community-based services (HCBS). That insufficient funding flows in part from Medicaid’s structural preference for nursing homes, a preference codified in the federal Medicaid statute. States participating in Medicaid must cover nursing home services; they are a

⁶¹ *The Striking Racial Divide in How Covid-19 has hit Nursing Homes*, N.Y. TIMES, Sept. 10, 2020, <https://nyti.ms/3e45iVv>.

⁶² Sidnee King & Joel Jacobs, *supra* note _____. The analysis was conducted by *The Washington Post*, using data compiled by Brown University from about 11,000 nursing homes, or nearly three quarters of all nursing homes in the United States. Another researcher described a similar but even starker finding: coronavirus cases and deaths were doubled at nursing homes with the highest percentage of non-white residents. *Id.* (describing the testimony of University of Chicago researcher R. Tamara Konezka before the Senate Special Committee on Aging in May 2020).

⁶³ Dylan Matthews, *America’s Covid-19 hot spots shed a light on our moral failures*, VOX, May 1, 2020, <https://www.vox.com/future-perfect/2020/5/1/21239396/covid-19-meatpacking-prison-jail-moral>.

mandatory benefit under federal law. By contrast, HCBS is an optional service. Accordingly, states can choose to provide HCBS or not and can limit how much they spend on HCBS.

After the Supreme Court’s 1999 holding that unjustified segregation of people with disabilities in institutions is a form of disability discrimination violating Title II of the ADA⁶⁴, the proportion of state funding devoted to HCBS has increased in most states. Even with federal and state policy initiatives to augment the availability of HCBS, the demand for Medicaid-funded HCBS continues to outstrip the supply in most states. “The result is waiting lists that in some states force eligible persons to wait years in order to access HCBS, and push them into nursing facilities in the interim.”⁶⁵ A report issued in October 2020 scoring states’ progress in providing long-term services and supports found improvement, but it was uneven; the gap between states providing the most support for HCBS and those providing the least support grew wider.⁶⁶

Not only does Medicaid’s structure continue to push disabled people into nursing homes when they would prefer to (and could, with support) live in their own homes, nursing homes overall remain relatively segregated by race. That segregation reflects a history of history of tepid (at best) civil rights enforcement against nursing homes.

⁶⁴ *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999).

⁶⁵ Carlson statement, *supra* note ____, at 12.

⁶⁶ *Long-Term Services & Supports State Scorecard, Advancing Action*, 2020 SCORECARD REPORT: MAJOR FINDINGS, <http://www.longtermscorecard.org/2020-scorecard/major-findings#footnote6> (data covers period 2016–2019). The widening gap resulted not only from some states spending significantly more on HCBS, but also from some states spending significantly less. The widening gap resulted not only from some states spending significantly more on HCBS, but also from some states spending significantly less.

Increased spending on HCBS to permit more disabled people to live in their homes and communities is certainly progress, in terms of respecting their human dignity, promoting inclusiveness, and removing people from a setting that is particularly dangerous from an infection transmission perspective. That said, providing supports in the community is not a panacea for the particular risks faced by disabled people during the pandemic. Most people receiving LTSS do not live in nursing homes, but both the people receiving those services and those providing them are particularly vulnerable during the pandemic. *Long-Term Services & Supports State Scorecard, Advancing Action*, 2020 SCORECARD REPORT: PREFACE, <http://www.longtermscorecard.org/2020-scorecard/preface>. Werner et al. describe how, although Medicaid has since 2013 devoted a majority of its spending for long-term care to home and community-based services, it fails to adequately pay for care provided by family members and other non-professional caregivers. Werner et al., *supra* note ____.

Because the Medicaid program is by far the largest payer for nursing home care in the United States, it is (in theory at least) subject to Title VI of the Civil Rights Act of 1964, which prohibits discrimination based on race by recipients of federal funding. In fact, it was the 1965 creation of Medicare and Medicaid – accompanied by the infusion of massive amounts of federal Medicare funding for hospital care for senior citizens—that provided leverage for a low-profile but successful effort by local civil rights leaders and staff from the federal Office of Equal Health Opportunity to integrate hospitals in the South. Basically, if hospitals wanted to retain access to that federal funding, they needed to desegregate.⁶⁷

Title VI enforcement efforts against nursing homes, by contrast, were limited and ineffectual, a “half-hearted pro forma paper compliance effort that everyone understood was cosmetic.”⁶⁸ This enforcement gap has historical roots. Although today Medicaid is the leading payer for nursing home services nationally, it paid for relatively few nursing home residents in its early years. In the 1960s, most nursing homes were small establishments – more akin to boarding homes than to hospitals – whose operators could choose not to admit Medicaid recipients into their facilities without suffering a severe financial penalty.⁶⁹ Over time, as Medicaid’s funding role grew, nursing home operators devised nuanced ways to maximize their flexibility to admit or reject patients covered by Medicaid, as it suited them. Rather than deciding that an entire facility would admit (or reject) Medicaid patients, those operators learned that they could choose to certify or de-certify individual beds for participation in the Medicaid program. Federal regulators tolerated nursing homes’ patient-by-patient decisions whether to participate in Medicaid.

⁶⁷ DAVID BARTON SMITH, *HEALTH CARE DIVIDED: RACE AND HEALING A NATION* (U. Mich. Press Ann Arbor 1999).

⁶⁸ Smith, *supra* note ____, at 246.

⁶⁹ Smith, *supra* note ____, at 246–50.

What does that have to do with racial segregation in nursing homes? Medicaid's low payment rates for nursing home care was the ostensible basis for nursing home operators' decisions to de-certify some beds for Medicaid, permitting them to be filled by more lucrative private-pay patients. But this bed-level flexibility granted operators tremendous discretion regarding which patients to admit or reject, with financial justifications likely masking racial discrimination in some cases. Even when race per se did not motivate decisions, the substantial overlap between disabled or elderly people who were low income (the basis for Medicaid eligibility) and disabled or elderly people who were Black meant that a pure-hearted commitment to profit maximization could have a racially discriminatory effect.⁷⁰ Indeed, one of the few cases where plaintiffs have successfully invoked Title VI in a health care setting involved nursing homes. In *Linton v. Tennessee*,⁷¹ a federal district court held that the Tennessee Medicaid program, by regulating nursing homes in a way that permitted them to give preference to private-pay patients, had a disparate and adverse impact on Black people in violation of Title VI.

Whatever the precise etiology, racial segregation in nursing homes continues and is connected to quality disparities.⁷² Research indicates that facilities that serve primarily residents who are Black or Latino tend to receive fewer stars in the government's nursing home rating system.⁷³ Although more research is needed to explain the disparities in case and fatality rates between majority-white nursing homes and majority-Black nursing homes, one plausible explanation is that racial segregation within the industry contributed to regulators' tolerance of

⁷⁰ See Sidney Watson, *Health Care in the Inner City: Asking the Right Question*, 71 N.C. L. REV. 1647, 1668 (1993)[confirm] ; Ruqaiyah Yearby, *Is It Too Late for Title VI Enforcement?: Seeking Redemption of the Unequal United States "Long Term Care System through International Means*, 9 DEPAUL J. HEALTH CARE L. 971 (2005).

⁷¹ *Linton v. Tennessee*, 779 F. Supp. 925 (M.D. Tenn. 1990).

⁷² Yue Li et al., *Deficiencies in Care at Nursing Homes and Racial/Ethnic Disparities Across Homes Fell, 2006-11*, 34 Health Aff. 1139 (2015).

⁷³ *Striking Racial Disparity*, *supra* note ____.

simmering quality and safety disparities in these facilities, disparities that came to full boil when the coronavirus hit.⁷⁴

When the coronavirus arrived, conditions in many nursing homes rendered them fertile ground for infection to spread. As with prisons, the inability of many nursing homes to prevent or control outbreaks of COVID-19 among their residents and staff should not have been a surprise, given tepid government enforcement of safety and quality standards before the pandemic. Many facilities have perennially operated with inadequate levels of poorly trained, minimum-wage staff and inadequate infection control measures.⁷⁵ An analysis conducted by the Government Accountability Office (GAO) examined nursing homes' infection prevention practices and found that from 2013 to 2017, 82% of facilities had received at least one citation for an infection prevention deficiency. In addition, a sizable number of facilities had repeated problems with infection-related quality measures. Almost half of the facilities cited had received citations for deficiencies in multiple consecutive years.⁷⁶ In the years immediately prior to the pandemic, the Centers for Medicare & Medicaid Services (CMS) curtailed its use of fines against nursing homes

⁷⁴ LaShyra T. Nolen, Adam L. Beckman & Emma Sandoe, *How Foundational Moments in Medicaid's History Reinforced Rather than Eliminated Racial Health Disparities*, HEALTH AFF. BLOG, Sept. 1, 2020, <https://www.healthaffairs.org/doi/10.1377/hblog20200828.661111/full/> (suggesting that racial segregation “may have contributed to worse quality of care and poorer outcomes for Black elderly individuals—and can be hypothesized as a likely contributor to the adverse outcomes observed in the older Black community during COVID-19”). Officials within the nursing home industry have asserted that the COVID-19 racial disparities in nursing homes reflects the disparities in the general population, so that nursing homes that are located in and draw their employees from hard-hit communities of color have been similarly hard hit.⁷⁴ But an analysis by the *New York Times* controlled for factors like the nursing home's size, residents' Medicare or Medicaid coverage, and the population density and infection rate in the surrounding area. When those variables are taken into account, the disparity remained between homes with a small proportion of residents of color and a large proportion. Striking Racial Divide, *supra* note ____.

⁷⁵ Carlson, *supra* note ____, at 2.

⁷⁶ Carlson, *supra* note ____, at 3, citing GAO, *Infection Control Deficiencies Were Widespread and Persistent in Nursing Homes Prior to COVID-19 Pandemic*, at 4-5 (May 20, 2020).

and rolled back an Obama-era mandate requiring nursing homes to have an infection preventionist on staff at least part time.⁷⁷

Regulatory inaction in the face of persistent deficiencies in infection prevention and control practices among nearly half of America's nursing facilities set the stage for the explosion of COVID-19 cases. Several months into the pandemic, CMS acknowledged what common sense suggests: nursing homes that performed poorly on quality inspections were more likely to have large numbers of COVID-19 cases.⁷⁸ At this writing, the evidence is mixed on the connection between nursing home quality and COVID-19 outbreaks.⁷⁹ What is clear, though, is that the choice not to enforce safety standards meant to protect the well-being of disabled people residing in nursing homes signals a devaluation of their lives and welfare.

Thus, the catastrophic impact that COVID-19 has had on disabled people forced to reside in nursing homes, with worse impacts on facilities with larger proportions of Black residents, was neither unpredictable nor unpreventable.

Placing Medicaid's lifeline out of reach

Numerous choices about Medicaid policy, both historical and recent, helped establish the backdrop against which the pandemic unfolded in ways particularly devastating to Black people and disabled people. Medicaid's structural preference for funding nursing home care over HCBS, discussed earlier, is one example. Other policies that some states have adopted, often with explicit approval by the federal government in the form of Medicaid waiver approvals, have made it harder for low-income persons to qualify for and enroll in Medicaid. Adopting policies like work

⁷⁷ Debbie Cenziper, Joel Jacobs & Shawn Mulcahy, *As pandemic raged and thousands died, government regulators cleared most nursing homes of infection-control violations*, WASH. POST, Oct. 29, 2020, <https://www.washingtonpost.com/business/2020/10/29/nursing-home-deaths-fines/>.

⁷⁸ Carlson, *supra* note ____, at 4, citing CMS, Nursing Home COVID-19 Data Release External FAQs, FAQ #25 (June 4 2020).

⁷⁹ Priya Chidambaram, Tricia Neuman, & Rachel Garfield, *Racial and Ethnic Disparities in COVID-19 Cases and Deaths in Nursing Homes*, Kaiser Family Foundation, Oct. 27, 2020.

requirements,⁸⁰ limitations on retroactive coverage,⁸¹ and abysmally low income eligibility thresholds⁸² all erect barriers to low-income people obtaining health coverage. One reporter described Medicaid as a “lifeline” during the pandemic,⁸³ referring to the program’s ability to provide coverage to people who have lost their jobs and health insurance during the pandemic. Choices made by some states and the federal government have placed that lifeline out of reach for many people without other coverage options. In fairness to the states, their decisions regarding Medicaid policies may be tightly constrained by budgetary necessities. Those decisions, however, often reflect implicit or explicit judgments about which low-income people are deserving or “worthy” of receiving publicly supported health coverage.⁸⁴

But the key choice regarding Medicaid that has contributed to exacerbating racial disparities in the pandemic has been the decision by twelve states (as of early 2021) to refuse to expand their programs as called for by the Affordable Care Act (ACA). A growing body of research demonstrates the positive impacts of Medicaid expansion on a wide range of health outcomes.⁸⁵ Expansion decisions are also consequential with regards to health care disparities, as

⁸⁰ Note how many states approved; implemented; currently paused. Mary Crossley, *Threats to Medicaid and Health Equity Intersections*, 12 ST. LOUIS U. J. HEALTH L. & POL’Y 311 (2019).

⁸¹ MaryBeth Musumeci & Robin Rudowitz, *Medicaid Retroactive Coverage Waivers: Implications for Beneficiaries, Providers, and States*, Kaiser Family Foundation, Nov. 10, 2017, <https://www.kff.org/report-section/medicaid-retroactive-coverage-waivers-implications-for-beneficiaries-providers-and-states-issue-brief/>.

⁸² As of January 1, 2020, Alabama’s income eligibility threshold for the parents of dependent children was set at 18% of the federal poverty level. *Medicaid Income Eligibility Limits for Adults as a Percent of the Federal Poverty Level*, Kaiser Family Foundation, <https://www.kff.org/health-reform/state-indicator/medicaid-income-eligibility-limits-for-adults-as-a-percent-of-the-federal-poverty-level/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>

⁸³ Bob Herman, *Medicaid will be a Coronavirus Lifeline*, AXIOS, Apr. 1, 2020, https://www.axios.com/medicaid-aca-coronavirus-lifeline-f71c3adc-c153-4069-97f6-fa439060ef71.html?utm_source=newsletter&utm_medium=email&utm_campaign=newsletter_axiosvitals&stream=top. [read Aron-Dine’s test’y re ACA/MCD as lifeline; CBPP in COVID-19 folder]

⁸⁴ Crossley, *supra* note ____.

⁸⁵ Madeline Guth, Rachel Garfield & Robin Rudowitz, *The Effects of Medicaid Expansion under the ACA: Updated Findings from a Literature Review*, Kaiser Family Foundation, Mar. 17, 2020, <https://www.kff.org/medicaid/report/the-effects-of-medicaid-expansion-under-the-aca-updated-findings-from-a-literature-review/>.

groups who have been disproportionately uninsured gain coverage and, with it, access to testing and care.⁸⁶

The Supreme Court, not Congress, is to thank for leaving it up to states to choose whether to expand their Medicaid programs. As enacted, the ACA required all states to expand their Medicaid programs to cover non-elderly persons with family incomes of up to 138% of the federal poverty level. This expansion would have made Medicaid available to an additional estimated 21.3 million persons who were previously ineligible for the program, many of them single or childless adults.⁸⁷ To ease the financial burdens on states, the ACA required the federal government fund 100% of the expansion through 2016, with the federal share then declining to 90% for 2020 and

⁸⁶ For example, one study found an association between expanding Medicaid and a significant increase in testing for HIV. Yunwei Gai & John Marthinsen, Medicaid Expansion, HIV Testing, and HIV-Related Risk Behaviors in the United States, 2010-2017, 109 Am J. Pub. Health 1404 (2019). Increased testing provides an opportunity to address the spread of HIV and to provide early treatment to those diagnosed with an infection. According to the CDC, in 2018, 42% of new HIV diagnoses were in Black Americans, who made up only 13% of the American population. Impact on Racial and Ethnic Minorities, HIV.gov, <https://www.hiv.gov/hiv-basics/overview/data-and-trends/impact-on-racial-and-ethnic-minorities>, accessed Dec. 17, 2020. See also Susan L. Hayes et al., *Reducing Racial and Ethnic Disparities in Access to Care: Has the Affordable Care Act Made a Difference?*, COMMONWEALTH FUND ISSUE BRIEF (Aug. 2017) (finding that the uninsured rate decreased more steeply among Black and Hispanic Americans than among whites, narrowing the gaps in coverage rates), https://www.commonwealthfund.org/sites/default/files/documents/media_files_publications_issue_brief_2017_aug_hayes_racial_ethnic_disparities_after_aca_ib.pdf. The study also found narrowing of the racial disparities in the percentage of people who reported skipping needed care because of costs and lacking a usual source of care. When focusing on expansion states as compared to non-expansion states, the study found that racial disparities in these access-related measures were smaller in states that chose to expand. Discerning the impact of a state's expansion of Medicaid, as compared to that of expanded coverage via Obamacare subsidies or other factors present in a state, is challenging. Even before the Medicaid expansion, indicators for all three access measures were lower (better) for all three racial groups and racial and ethnic disparities were narrower in the states that chose to expand, reflecting that these states had more generous eligibility standards even before the ACA. In these states, expansion seemed to offer the greatest benefit for Hispanics, in terms of the narrowing of disparities between 2013 and 2015.

⁸⁷ John Holahan et al., *The Cost and Coverage Implications of the ACA Medicaid Expansion: National and State-by-State Analysis*, Kaiser Comm'n on Medicaid & the Uninsured 1, Nov. 2012, <https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8384.pdf>.

thereafter.⁸⁸ In 2012, however, the Supreme Court’s decision in *NFIB v. Sebelius*⁸⁹ effectively transformed the ACA’s expansion mandate to an option for the states.

Although the Medicaid portion of *NFIB* was decided on the basis of a previously unapplied “coercion” theory under the Spending Clause, the majority opinion contains distinct echoes of “states’ rights” rhetoric, a rhetoric historically employed to preserve states’ ability to discriminate and pursue white supremacist policies.⁹⁰ Exploring the historical precedent of New Deal social welfare legislation that preserved implementation discretion for states, historian Tomiko Brown-Nagin characterizes the approach as “amount[ing] to an imprimatur to discriminate against disfavored groups, including blacks and others deemed unworthy of charity because of color or perceived moral failing.”⁹¹ Brown-Nagin thus provides historical context for Chief Justice Roberts’ conclusion that states must be permitted to decide — without coercion from the federal government — whether to extend Medicaid coverage to all low-income adults, reasoning that predictably produces “profound results.”⁹²

Even before the Court decided *NFIB v. Sebelius*, the racial equity implications of making the Medicaid expansion optional with the states were foreseeable. People of color, who as a group were disproportionately likely to be uninsured and to have low incomes, constituted a majority of people who would benefit from the expansion. But the differential impact of non-expansion decisions was foreseeable, even at the time that the Court decided *NFIB*. Analyses of Medicaid and the expansion’s predicted effects were available to the Court, leading constitutional law

⁸⁸ By contrast, the federal government pays a much smaller share of the Medicaid costs of other enrollees, ranging from paying 73% of Medicaid costs in the poorest states to paying only 50% in wealthiest states. *See* Center for Budget and Policy Priorities, Policy Basics: Introduction to Medicaid (Aug. 16, 2016), <https://www.cbpp.org/research/health/policy-basics-introduction-to-medicaid>.

⁸⁹ *National Federation of Independent Business v. Sebelius*, 567 U.S. 519 (2012).

⁹⁰ *See* Tomiko Brown-Nagin, *Two Americas in Healthcare: Federalism and Wars over Poverty from the New Deal-Great Society to Obamacare*, 62 *DRAKE L. REV.* 101 (2014).

⁹¹ *Id.* at 110.

⁹² *Id.* at 104.

scholar Stephen Griffin to conclude: “The tragedy of the Medicaid expansion is that it was fairly foreseeable that the burden of the Court’s decision would fall on the backs of extremely impoverished adults in southern states and that this burden would be strongly connected with America’s historic burden of race.”⁹³ Pointing to a study indicating that southern states were among the worst performing health care systems, including having wide racial disparities in mortality,⁹⁴ Griffin concluded that the Medicaid expansion provision of the ACA represented a decision by the federal government to address the troubling and historically rooted pattern of health inequality in the U.S. and that, through the decision in *NFIB*, “the Court permitted the states to reinstate inequality.”⁹⁵

And many of the states that to date have refused to expand their Medicaid programs pursuant to the ACA are southern states, with large Black populations.⁹⁶ Among Black people who stood to gain insurance from the Medicaid expansion, nearly 60% lived in states that initially chose not to move forward with the expansion,⁹⁷ meaning that Black people were disproportionately left behind when the Medicaid expansion became optional for states.⁹⁸ Many poor adults who stood to

⁹³ Stephen Griffin, *The Tragedy of the Medicaid Expansion: A Story of Race and Federalism (Part I)*, Balkinization blog, Feb. 28, 2017, <https://balkin.blogspot.com/2017/02/the-tragedy-of-medicaid-expansion-story.html>

⁹⁴ David C. Radley et al., *Aiming Higher: Results from a Scorecard on State Health System Performance, 2014*, at 27, The Commonwealth Fund, May 2014, https://www.commonwealthfund.org/sites/default/files/documents/___media_files_publications_fund_report_2014_apr_1743_radley_aiming_higher_2014_state_scorecard_corrected_62314.pdf

⁹⁵ Stephen Griffin, *The Tragedy of the Medicaid Expansion (Part III)*, Balkinization blog, March 18, 2017, https://balkin.blogspot.com/2017/03/the-tragedy-of-medicaid-expansion-part_18.html

⁹⁶ See Samantha Artiga et al., *Changes in Health Coverage by Race and Ethnicity since Implementation of the ACA, 2013-2017*, Kaiser Family Foundation (Feb. 13, 2019), <https://us.bbcollab.com/guest/cc6faec0be1e452cb2e278c47dc0d37c>.

⁹⁷ Kaiser Commission on Medicaid and the Uninsured, *Issue Brief, The Impact of Current State Medicaid Expansion Decisions on Coverage by Race and Ethnicity*, July 2013, http://www.statecoverage.org/files/KFF_Impact_Medicaid_Expansion_Decision.pdf.

⁹⁸ Cf. Madeline Guth, Samantha Artiga & Olivia Pham, *Effects of the ACA Medicaid Expansion on Racial Disparities in Health and Health Care*, Kaiser Family Foundation, Sept. 30, 2020, <https://www.kff.org/medicaid/issue-brief/effects-of-the-aca-medicaid-expansion-on-racial-disparities-in-health-and-health-care/> (research findings show that the Medicaid expansion has helped reduce racial disparities in health coverage).

gain health coverage under the expansion are left uncovered.⁹⁹ In fact, people of color in non-expansion states disproportionately fall into a “coverage gap,” a term describing the situation of persons who cannot enroll in Medicaid because their state has not expanded and who also are ineligible for the federal subsidies for purchasing private insurance (popularly known as Obamacare) *because their incomes are too low*.¹⁰⁰ People in the coverage gap are bereft of any of the coverage-related benefits of the ACA. Uninsured Black adults were more than twice as likely to fall into this unenviable category, as compared to both whites and Hispanics.¹⁰¹ This disproportionate representation of Black people in the coverage gap results from the decisions of many Southern states not to expand.¹⁰²

Recognition that people of color are particularly disadvantaged by states’ non-expansion decisions has prompted consideration of whether and how race may have influenced those decisions. After critically examining stated justifications for states’ leaving untapped millions of federal dollars to provide health coverage for their low-income residents, health law scholar Mark Hall found that only “crass political motivation (that some might think is racially tinged) [or] obstinate ideology” could explain states’ “stubborn refusal.”¹⁰³ An analysis of public opinion in non-expanding states found evidence that public support for the expansion was racialized and that

⁹⁹ See Christina Andrews et al., *The Medicaid Expansion Gap and Racial and Ethnic Minorities with Substance Use Disorders*, 105 AM. J. PUB. HEALTH SUPP. 3 S452 (2015). Explain the cruel irony of the coverage gap.

¹⁰⁰ See Rachel Garfield et al., *The Coverage Gap: Uninsured Poor Adults in States that Do Not Expand Medicaid*, Kaiser Family Foundation (June 12, 2018), <https://www.kff.org/medicaid/issue-brief/the-coverage-gap-uninsured-poor-adults-in-states-that-do-not-expand-medicaid/>.

¹⁰¹ Samantha Artiga et al., *The Impact of the Coverage Gap for Adults in States not Expanding Medicaid by Race and Ethnicity*, Kaiser Family Foundation (Oct. 2015), <https://www.kff.org/disparities-policy/issue-brief/the-impact-of-the-coverage-gap-in-states-not-expanding-medicaid-by-race-and-ethnicity/>.

¹⁰² See Kaiser Family Foundation, *Issue Brief: The Impact of the Coverage Gap in States not Expanding Medicaid by Race and Ethnicity* (Dec. 2013), <https://kaiserfamilyfoundation.files.wordpress.com/2013/12/8527-the-impact-of-the-coverage-gap-in-states-not-expanding-medicaid.pdf>.

¹⁰³ Mark A. Hall, *States’ Decisions Not to Expand Medicaid*, 92 N.C. L. REV. 1459,1477–78 (2014).

states' decisions tended to reflect white support (or nonsupport) for expansion. and not nonwhites' support.¹⁰⁴

The shortsightedness of racially influenced non-expansion decisions is both chillingly and poignantly portrayed in Jonathan Metzl's excellent book *Dying of Whiteness: How the Politics of Racial Resentment is Killing America's Heartland*¹⁰⁵. One of Metzl's case studies of how entrenched racism affects white people explores why Tennessee, once "a Southern beacon for progressive approaches to health care for low-income people,"¹⁰⁶ became a Medicaid expansion holdout, despite the efforts of a Republican governor to implement the expansion. Listening to focus groups of men revealed historically grounded and racially inflected negative responses to "government" among many white men, as well as a conviction that expanding Medicaid would mean having to pay for Black people and immigrants. Ultimately, according to Metzl, having health care reform as a common enemy provided white men with beneficial group cohesion and an affirmation of the value of their whiteness, even as it deprived them of access to needed health care. From this perspective, perceived threats to white racial status and privilege fueled Tennessee's objectively self-defeating decision to reject the Medicaid expansion, a rejection that carried enough harm to go around. Metzl estimated that the State's "refusal to expand Medicaid cost *every single* white resident of the state *14.1 days of life*."¹⁰⁷ Even as Black people in the south have been disproportionately disadvantaged by refusals to adopt the Medicaid expansion, their white neighbors have suffered too.

¹⁰⁴ Colleen M. Grogan & Sunggeun (Ethan) Park, *The Racial Divide in State Medicaid Expansions*, 42 J. HEALTH POLITICS, POL'Y & L. 539 (2017).

¹⁰⁵ JONATHAN M. METZL, *DYING OF WHITENESS: HOW THE POLITICS OF RACIAL RESENTMENT IS KILLING AMERICA'S HEARTLAND* (Basic Books 2019).

¹⁰⁶ *Id.* at 133.

¹⁰⁷ *Id.* at 13.

In sum, a critical examination of the Court's *NFIB v. Sebelius* decision and non-expanding states' response to it reveals another dimension of how the disproportionate burden of illness and death experienced by Black Americans during the COVID-19 pandemic – at least in non-expanding states – is the result of choices with predictable results.

Conclusion: Looking Forward

Life is filled with choices; some are more consequential than others. An emergency presents choices that demand quick responses, and a public health emergency requires choices where lives hang in the balance. The COVID-19 pandemic is no exception. Issues of equity pervade these choices, whether or not policymakers and public discern or care about those issues. This essay has focused on how political and legal choices made prior to the pandemic contributed to the tragic and unjust burden of illness and death that Black and disabled Americans have borne during the pandemic. One of my purposes, however, is to use an increased visibility of the constructed nature to health vulnerability to urge greater attention to issues of equity going forward during the pandemic and after.

Choices already presented during the pandemic have risked imposing excessive burdens on disabled people and Black people in myriad ways. As coronavirus hospitalizations mounted in several locales early in the pandemic, the prospect that inadequate resources—and particularly an insufficient number of ventilators—might require triage decisions devaluing disabled lives loomed large. In another example, hospitals with the highest shares of revenues received twice as much of the early distribution of relief funding from the CARES Act, as compared to hospitals with the lowest share, namely hospitals that serve large numbers of patients who are uninsured or have

Medicaid coverage.¹⁰⁸ Disadvantaging safety net providers predictably disadvantages the patients who rely on them for care. Health law scholar Courtney Anderson observes that it wasn't until the pandemic caused housing instability for higher-income people that eviction-protection measures were enacted, and even that short-term fix failed to address many of the housing needs of low-income persons and people of color.¹⁰⁹ Many more examples could be given.

Increasingly, advocates for health equity have demanded that equity explicitly be made central to policy decisions and implementation strategies during and following the pandemic. Naming the historical choices that predictably resulted in unjust disparities already suffered by Black people and people with disabilities in the pandemic should spur us to recognize how important it is for us, going forward, to make choices that will mitigate and repair those disparities.

¹⁰⁸ Nolan et al., *supra* note ____.

¹⁰⁹ Courtney Lauren Anderson, *A Pandemic Meets a Housing Crisis*, Assessing Legal Responses to COVID-19 187, Aug. 2020, www.covid19policyplaybook.org.