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The ADA at 31

Access to Housing and Health Care Must Meet the Rise of Disability in the U.S.

By Valerie Novack and Kelly Moh August 5, 2021

It has been nearly 50 years since disability activists in San Francisco took over a federal building for 28 days to force the signing of Section 504 of the Rehabilitation Act.[1] This legislation established the rights of people with disabilities against discrimination in programs receiving federal funds. By 1990, disability activists were literally crawling up the steps of the U.S. Capitol to demand civil rights legislation for disabled people.[2] This resulted in the passage of the Americans with Disabilities Act, which celebrated its 31st anniversary in July 2021. Yet even with these laws' protections, the lack of access and equity for people with disabilities—particularly those who are multiply marginalized—was put in sharp focus by their treatment during the COVID-19 pandemic.

Despite the coronavirus being indiscriminate, it has laid bare the inequities of the United States for all to witness. COVID-19 killed hundreds of thousands of Americans in part due to the vulnerability created through continued inequities in the distribution of resources and services, particularly in marginalized populations.[3] Little has been done to make permanent changes to decrease these fatalities and better and more equitably protect against future pandemics and other crises for communities of color, disabled and older people, and low-income neighborhoods.

Despite the passage of several temporary measures to better support people in the United States—including increased economic support,[4] access to health care testing and vaccines, and eviction and foreclosure protections[5]—housing, food, and health care still have not been determined as basic rights to maintain public health and safety. And worse yet, wages have not been raised for those working minimum and subminimum wage jobs. As the country has faced—and continues to face—many challenges in health care, housing,[6] and the economy,[7] few things have changed in any permanent way in the governing of lives, even as everything has changed for those who have been directly touched by the coronavirus.

The disparities in COVID-19 outcomes such as cases and deaths are not surprising. Factors outside of the traditional health care system have tremendous effect on health outcomes, potentially determining up to 90 percent of overall health.[8]

These factors are referred to as the social determinants of health, which include areas such as education, food access, and housing.[9] Although there has historically been a general understanding of the impact of these factors on health, it is now becoming more common knowledge. The Centers for Disease Control and Prevention (CDC) and the U.S. Department of Health and Human Services' Healthy People initiative first set objectives for improving health and well-being nationwide in 1990 and is updated every 10 years; with the release of Healthy People 2030,[10] the initiative has increased its focus on health equity, social determinants of health, and health literacy. Yet health inequities continue to exist.

The coronavirus crisis has shown how precarious access is to services that affect health care for many people in the United States. For example, the history of discrimination in neighborhood investment and health care in communities of color contributed to the increased likelihood of mortality from COVID-19 in Black, Latino, Asian, Pacific Islander, and Native American populations.[11] Moreover, after not honoring, investing in, or enforcing rights of access and community living for people with disabilities, the United States faced staggering death rates in long-term living facilities, which have accounted for nearly one-third of COVID-19 deaths in the country.[12] Meanwhile, low wages, lack of protections, and a shortage of direct service workers increased the risks for residents and workers in nursing homes, the 12 million disabled and older individuals who rely on the services of direct service professionals in their private homes,[13] and both parties' families, who are often living in poverty.[14] The need for meaningful supports will only be expanded with post-pandemic increases in disability due to long-haul COVID-19 symptoms, mental health challenges, and delayed health care services.

In order to sufficiently care for the current population and to better prepare for the future of the United States, care infrastructure must be funded and expanded throughout the life course; the minimum wage and social supports such as food access must be increased; and infrastructure must be equitably invested in to create resilient communities for all people.

The growth of the disability population

Disability is not uncommon in the United States. In 2018, the CDC estimated that 1 in 4 people in the country have a disability.[15] Despite this, resources and supports are underfunded and understaffed. A 2018 analysis of the U.S. health workforce by Mercer estimated that by 2025, there will be a shortage of 446,000 direct service workers as well as nearly 100,000 lab and medical techs, 95,000 nursing assistants, and 30,000 nurse practitioners.[16] Even in 2018, prior to a pandemic that overwhelmed the health care system, this shortage was of concern to maintaining health care quality; and it has since contributed to increases in doctors and nurses

leaving their jobs,[17] with 8 percent of doctors closing their practices altogether in 2020[18]—an estimated loss of 16,000 practices.[19] This reduction of health care providers amid the pandemic only worsened the shortage.

Additionally, a recent study on COVID-19 cases showed that about one-third of people with mild cases experienced at least one symptom that has lasted longer than six months—a potential increase of millions of people with symptoms from stroke to hypertension to fatigue.[20] The mental health toll of this pandemic and long COVID-19 is also concerning.

Racial tensions arising from racist rhetoric and other factors have significantly affected the mental health and well-being of Black, Latino, and Asian American and Pacific Islander (AAPI) communities, particularly during the pandemic. Recently, the extensive reporting around police violence against Black people has resulted in countless protesters marching in the streets, with studies indicating that the uptick in highly public anti-Black police violence has resulted in significant mental health distress for this population.[21] Asian Americans have also experienced an increase in mental health issues during the pandemic. According to Stop AAPI Hate, an organization formed during the pandemic to track the growing number of anti-Asian incidents, there were 6,603 hate incidents against Asian Americans from March 2020 to March 2021.[22] As a result, anxiety, depression, and PTSD symptoms have also increased in the Asian American population. Racist rhetoric, particularly from the previous administration, helped catapult this anti-Asian discrimination around the country.[23]

With the CDC recently declaring racism a public health issue,[24] disparities faced by communities of color need to be addressed. The mental health needs of AAPI, Black, Indigenous, and other people of color cannot continue to be overlooked, and stigmas regarding mental health should be considered. With mental health disability increasing[25] and the health care system still lacking in mental health parity,[26] the United States is spiraling toward an onslaught of needs with systems unfit to meet it.

There are several crises forming or growing concurrently. The potential increase in long-term care needs for those with long COVID-19, coupled with the reduction in health care professionals in a field already experiencing shortages, could lead to additional strain in the future. Furthermore, a large aging population will continue to expand the need for accessible and integrated housing solutions as well as increased health and care infrastructure. Finally, increases in wealth gaps, climate disaster impacts, and migration will affect housing, income, and health stability. If America's systems were overwhelmed and unsuccessful in 2020, they most certainly will be met with greater fatalities in future crises—unless permanent changes are implemented.

The tolls of segregated services and discrimination

Congregate settings, namely nursing homes and prisons, disproportionately saw high rates of COVID-19 cases during the first few months of the pandemic. Many of the residents living in long-term facilities already had preexisting medical conditions, such as heart disease and chronic illnesses, increasing their susceptibility to contracting—and dying from—the virus. Nursing homes also lacked sufficient personal protective equipment (PPE) and had trouble procuring regular COVID-19 testing for their residents and staff. Additionally, in states such as New York, thousands of patients who tested positive for COVID-19 were sent back to nursing homes to free up space in hospitals.[27] However, the high death rates could have been prevented; going forward, this population cannot be neglected.

Along with the lack of PPE in long-term care facilities, prisons also experienced severe coronavirus outbreaks. According to a study published in July 2020, the rate of inmates who were infected by COVID-19 was more than five times that of the overall U.S. population.[28] The insufficient number of individual spaces to quarantine inside prisons resulted in overcrowding and increased mortality. Inmates—who are disproportionately people of color due to systemic racism[29]—share rooms, bathrooms, and dining spaces, making it incredibly difficult to accommodate social distancing. The recognition of incarcerated people as especially at-risk resulted in demands for their prioritization in vaccine phases.[30]

There has also been inequitable resource access for disabled individuals during the pandemic. Many of the websites used to sign up for vaccine appointments are not fully accessible,[31] providing barriers to people who use screen readers, for example. Additionally, some websites are hard to navigate, making the process more confusing for people who have language barriers or limited access to technology.[32] Physically getting to vaccination locations also proves to be an obstacle for disabled people who do not drive. On top of this, in early vaccine rollouts, people of color were less likely to have access to the vaccine due in part to the same or similar practices of discrimination in public health that led to increased COVID-19 deaths,[33] affecting those with intersecting identities of race and disability.

Overall, people with disabilities and their caregivers have been overlooked in vaccination rollout plans,[34] even though many are at high risk for COVID-19.[35] State- and community-level efforts have attempted to cover populations that lacked access, such as those unable to leave their homes.[36] In addition, targeted measures have helped increase access to the vaccine. Both indicate that better outcomes are achievable and that adjustments can be made for future implementation.

Massive impact should lead to massive response through change

Following a crisis, it is not unusual to make big changes to how the United States functions. During the Great Depression, President Franklin D. Roosevelt created the Works Progress Administration by executive order and created jobs for more than 8.5 million people in eight years across numerous sectors.[37] Specifically, the GI Bill allowed 2.4 million veterans to purchase homes and nearly 8 million to pursue additional training and education in roughly 10 years following World War II.[38] In 2008, the GI Bill was amended again in the wake of 9/11: A number of policy changes regarding safety, privacy, and foreign policy were adopted and are still in place today.[39]

Yet the failures expressed in America's health care, schooling, and quality of life have not been addressed in any permanent way since the coronavirus took more than 600,000 lives and U.S. life expectancy declined by the largest margin since the 1940s.[40] The previous administration refused to take the necessary steps to build resilient communities that could be better equipped to face current and future crises. And the current administration has been hesitant and slow to use its own bully pulpit, despite opportunities to do so.

Recommendations

Below are areas the United States must address to create a more equitable and resilient nation throughout the COVID-19 pandemic and in future crises.

Care infrastructure

The United States must reimagine how it provides care, whether for children or adults who need assistance. Funding has recently been set aside in the American Rescue Plan (ARP) of 2021 that would allow for a reduction of the Medicaid home- and community-based services (HCBS) waiver waitlist for housing and lessen the number of residents in nursing homes.[41] However, the funding does not meet the need for permanent and consistent funding for long-term services and supports or for waiver programs in each state,[42] which must be expanded to include increased compensation for direct care workers and permanent funding for the Money Follows the Person program.[43] Paid family leave, universal health care, and child care resources are also needed to allow for individuals already living within their communities to join or rejoin the workforce, support their family, and/or to adjust to the new reality of their lives.[44]

Equitable community investment

Wealthy neighborhoods have disproportionate access to services and goods. These disparities create socially vulnerable neighborhoods where health and other outcomes are negatively affected by social factors and regulatory choices in develop-

ment.[45] Despite the public and personal health and economic benefits to shelter, as well as the legal protection of the right for community living, housing has not been established as a legally protected right in the United States. And unfortunately, the recent infrastructure bill provides no funding for affordable housing maintenance or construction.[46] While the Build Back Better Plan has pushed to provide funding for subsidized housing, rental assistance, and improvements to public housing, the agenda is still in negotiation.[47]

Mitigation of climate disasters

U.S. housing and infrastructure are at risk from not only disinvestment but also climate disasters. Currently, 57 percent of all structures in the United States are in a natural disaster hotspot,[48] while the past several years have seen unprecedented death and destruction from climate disasters, such as the recent deaths of hundreds of people in Texas due to power outages.[49] These outcomes often have the greatest impact on disabled people of color, who are at increased risk for loss of utilities, damages, and death in these and other areas.[50]

Robust social supports

Many parts of the United States are becoming increasingly unlivable financially. From March to October 2020, there was a 60 percent increase in food pantry usage.[51] Moreover, with the end of the eviction moratorium, 4.2 million renters said they are at risk of losing their homes in the next two months.[52] Roughly 30 percent of the workforce makes less than $15 per hour,[53] with many also lacking health care options, paid leave, retirement, and other benefits. It is imperative that social programs, such as the Supplemental Nutrition Assistant Program (SNAP), renter protections and assistance, unemployment insurance, Social Security, and disability insurance, are increased to better match need and align with the cost of living in the United States.

The requirements to apply for disability benefits should also be reviewed to ensure access for those needing it. Additionally, means testing and asset limits should be reviewed, as they restrict the ability of people with disabilities and others to save for emergency situations, creating more vulnerabilities in these populations.[54]

Conclusion

Those directly affected by COVID-19 already comprise a large portion of the U.S. population, but they are also a potentially growing segment. Not creating permanent, bold policy, practice, and infrastructure changes that support the needs of these populations will result in greater loss of life and a lack of preparedness when the next crisis comes.

In the past decade, it has become increasingly irresponsible to ignore the signs of vulnerability in the country's structures and residents due to negligent and slow-moving policy—that is, not investing in the social context in which people, particularly marginalized populations, live. While these vulnerabilities were laid bare by the coronavirus crisis, they exist beyond this pandemic. COVID-19 is not the first or the last event that will overburden systems and create a sudden increase in residents with disabilities, but policymakers and leaders can better prepare for events to come. The United States must take significant steps now to be resilient for the future.

Valerie Novack is a fellow with the Disability Justice Initiative at the Center for American Progress. Kelly Moh is an intern with the Disability Justice Initiative at the Center.

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