

Introduction

Good Morning. Thank you to Chairwoman Murray, Ranking Member Burr, and Members of the Committee, for inviting me to speak today.

I testify today not only as someone who has spent more than a decade in disability policy but also as a Black woman who lives with multiple chronic conditions. And, as someone who has seen and personally felt the devastating impacts of the pandemic on communities of color and people with disabilities.

The Magnitude of the Crisis

First, I will note where we are today.

According to the Centers for Disease Control and Prevention (CDC), as of March 22, 2021, 539,517 people in the U.S. have died from COVID-19. Nationwide, as of March 12, Black people have died at 1.9 times the rate of white people.¹ Hispanics and Latinos are 3.1 times more likely to be hospitalized from COVID-19 and 2.3 times more likely to die from COVID-19.² And, from January to June 2020, American Indians and Alaska Natives were 3.5 times more likely to be diagnosed with the disease than non-Hispanic whites and their mortality rate was almost twice as high.³

The stark disparities are also apparent for the disability community.

The CDC reported that all people seem to be at higher risk of severe illness from COVID-19 if they have serious underlying chronic medical conditions. As of February 11th among states reporting data, there were 111,000 cases and over 6,500 deaths, resulting in a fatality rate of 5.9 percent for people with disabilities.⁴ Even more startling, a cross-sectional study of nearly 65 million patients revealed that having an intellectual disability was the strongest independent risk factor measured for presenting with a COVID-19 diagnosis and the strongest independent risk factor other than age for COVID-19 mortality.⁵

Factors that Exacerbated the Crisis

¹ Centers for Disease Control and Prevention. Risk for COVID-19 Infection, Hospitalization, and Death By Race/Ethnicity. 03/12/21

² Ibid.

³ Talha Burki. "COVID-19 Among American Indians and Alaska Natives." *The Lancet: Infectious Diseases*. March 2021.

⁴ MaryBeth Musumeci and Priya Chidambaram. "COVID-19 Vaccine Access for People with Disabilities" KFF: March 01, 2021

⁵ Shaun Heasley. "Intellectual Disability Among Greatest COVID-19 Risk Factors, Study Finds." *Disability Scoop*. March 10, 2021

In order to ensure a comprehensive response to the pandemic, it is incumbent upon us to understand the factors that have shaped this crisis.

People with Disabilities

The 1999 Supreme Court case *Olmstead v. L.C.* confirmed that people with disabilities have the right to receive care within an integrated community or home setting.⁶ Yet preserving access to resources and home and community based services (HCBS) has been an ongoing challenge. Absent this critical funding, people with disabilities are compelled to live in settings such as nursing homes, group homes, or institutions. And, as we have seen, these settings can be deadly.

Equally critical in this moment is the ongoing fight for equal protection under the law, particularly in medical settings. In the past year, the disability community has feared and fought to prevent health care providers from withholding or withdrawing life-sustaining treatment on the basis of arbitrary standards about quality of life.⁷ We know that calculations made in these critical moments are at great risk to be colored by bias and stereotypes. In short, they are subject to ableism. The ongoing devaluing of the lives of people with disabilities that gives rise to discrimination, and the belief – entrenched within our policies and systems – that disabled lives are not worth saving.

Racial and Ethnic Minorities

In addition to ableism, we must discuss racism and the ways it contributes to disparate outcomes during the pandemic. As noted, COVID-19 has ravaged communities of color, which includes people with disabilities. In these communities, we see the ways in which poverty and its correlates: low wages, inadequate leave, lack of affordable housing, and a lack of affordable healthcare have been inextricably linked to higher rates of infection and mortality from COVID-19.⁸

Far from coincidental, the relationship between racial and ethnic minorities, low wages and the results: inadequate housing, healthcare, and poorer health outcomes is by design. Our society has codified a two-tiered economic system that overwhelmingly excludes Black and Brown workers, women, and people with disabilities from opportunities to earn competitive wages and have their basic needs met. With this

⁶ *About Olmstead*. Retrieved on March 22, 2021 from: https://www.ada.gov/olmstead/olmstead_about.htm

⁷ Joseph Shapiro. “People with Disabilities Fear Pandemic Will Worsen Medical Biases.” NPR: Morning Edition. April 15, 2020

⁸ Molly Kinder and Martha Ross. “Reopening America: Low-wage workers have suffered badly from COVID-19 so policymakers should focus on equity.” Brookings Institution. June 23, 2020.

history, it is no wonder that we have observed some of the worst outcomes of COVID-19 among these communities.

Steps Forward for Improved Equity and Outcomes

Data Collection

We cannot begin to understand or come up with improved policy without comprehensive data not only on fatalities, but also on infection and COVID-19 long haulers. Indeed, a measurable improvement in the equitable response of the pandemic can only occur with ongoing collection and reporting of all COVID-19-related data by race, ethnicity, socioeconomic factors and disability. Many states do not publish vaccine data that includes race and ethnicity and – a year into the pandemic - no comprehensive data exist detailing the full extent of the pandemic on people with disabilities throughout the U.S.

Equitable Vaccine Roll-Out

As the U.S.’s efforts to vaccinate our communities continue to scale-up, we need to take steps to ensure a more equitable rollout of the COVID-19 vaccines. The distribution of vaccines should take into account the disproportionate impacts that the pandemic has had on marginalized communities.⁹ This includes taking steps to ensure that communities of color and people with disabilities are prioritized in vaccination efforts.

Investment in Home and Community Based Services

It is imperative that people receiving care can remain in their homes and communities, rather than be admitted to crowded, unsafe congregate care settings—particularly during an ongoing pandemic and as we move into the future. We were pleased to see the addition of dedicated funding to HCBS in the American Rescue Plan (ARP), we applaud Representative Dingell and Senators Brown, Casey, Hassan for their release of a discussion draft of the HCBS Access Act and look forward to working with Congress to ensure that states have the resources they need to enable people with disabilities and older adults to live in their communities.^{10 11}

Investment in Affordable Healthcare

My colleagues at CAP have noted that while the coronavirus crisis has led to significant job loss in the United States, it has not been as severe of an increase in un-insurance as

⁹ Jamila Taylor. “The Path Towards Equity in COVID-19 Vaccination.” The Century Foundation. March 15, 2021.

¹⁰ American Rescue Plan of 2021. Retrieved from Congress.gov on March 23, 2021.

<https://www.congress.gov/bill/117th-congress/house-bill/1319/text>

¹¹ Michelle Diamant. “Waiting Lists May Be Eliminated for Disability Services Provided by Medicaid.” Disability Scoop. March 22, 2021

predicted earlier in the pandemic.¹² This is in part because the programs established by the Affordable Care Act (ACA) are robust, helping those who lost their jobs in the past year secure new sources of coverage. Ongoing support of the ACA and its role in expanding access to healthcare in the US is critical.

Medicaid Expansion

Equally important is support for Medicaid expansion.¹³ One way that Congress can act to expand coverage is to further incentivize state Medicaid expansion. States that have yet to expand Medicaid under the ACA have left millions of people—whose incomes are below the federal poverty level—without access to either Medicaid coverage or financial assistance toward marketplace coverage.¹⁴

Increased Wages and Access to Affordable Housing

To guarantee an equitable recovery, we urge Congress to address the low wages that keep people in poverty. An increased minimum wage, basic worker protections like the rights to form a union and receive overtime pay coupled with access to paid family and medical leave stand to benefit the marginalized communities that have been most impacted by this crisis. In addition to wages, it is critical that we continue to provide support for individuals who are housing insecure. The ARP's investments in assistance for renters, landlords and individuals who are at risk for homelessness is an important first step towards addressing a key risk factor for poor health outcomes.¹⁵

Conclusion

It may not be possible to avert another pandemic. However, it is certainly within our power to ensure that the next one doesn't devastate individuals, families and communities to the extent that we have seen in the last year. In the coming months, we should work hard to identify what went wrong, take action, and be undeterred in our effort to commit the investments necessary to guarantee a better future.

¹² Emily Gee and Thomas Waldrop. "Policies to Improve Health Insurance Coverage as America Recovers From COVID-19" Center for American Progress. March 11, 2021

¹³ Ibid.

¹⁴ Ibid.

¹⁵ American Rescue Plan of 2021. Retrieved from Congress.gov on March 23, 2021.

<https://www.congress.gov/bill/117th-congress/house-bill/1319/text>