

Testimony for the Record
Submitted by UsAgainstAlzheimer's to the
U.S. House of Representatives Committee on Ways and Means
Hearing on "The Disproportionate Impact of COVID-19 on Communities of Color"

On behalf of UsAgainstAlzheimer's, we write to thank the Committee for its leadership during the COVID-19 crisis, and to submit these comments for the record. As the Committee works to examine the causes, impacts and solutions related to COVID-19 health disparities, we urge you to consider the impacts on many of the 5.8 million Americans living with Alzheimer's disease and related dementias and on their nearly 16 million caregivers.

As you are aware, COVID-19 is having a devastating impact on older Americans and racial and ethnic minorities. According to the APM Research Lab, aggregated deaths from COVID-19 in the 40 states and the District of Columbia that have reported data by race and ethnicity demonstrate deep inequities across communities of color: Asians, Latinos and Blacks are dying at higher rates than whites – with Blacks dying at more than twice the rate as whites. The brunt of the disease is still not known among low income, limited-English-speaking populations who may not have access to timely, accurate information.

This data makes clear that the COVID-19 pandemic is having severe health impacts on our nation's most vulnerable communities and we know that these health effects are resulting in tremendous financial strain for families and our nation's economy. An April UsAgainstAlzheimer's survey found that 61% of caregivers are more concerned about their financial health and their family's finances than before the coronavirus pandemic.

Millions of unpaid family caregivers who are the frontlines of providing dementia care during this crisis have been overlooked in previous COVID-19 response legislation. Without continued efforts to address the economic impacts of COVID-19, the virus could exacerbate existing economic inequities experienced by caregivers, particularly caregivers of color.

To adequately address the intersectional impacts of COVID-19 on communities of color and the dementia community, UsAgainstAlzheimer's recommends Congress take action to increase economic support for unpaid family caregivers and to continue to press the Department of Health and Human Services for better reporting on the effects of COVID-19 by race and ethnicity. Specifically, UsAgainstAlzheimer's urges Congress take the following actions:

Recommendation 1: Expand paid leave benefits to support family caregivers of older adults living with chronic conditions.

Family caregivers for people living with Alzheimer's provide an estimated 18.4 billion hours of unpaid care – valued at \$244 billion annually. Comprehensive paid family and medical leave is critically important for these families.

We were heartened to see expanded protections for our nation's 50 million family caregivers in the HEROES Act. The crisis triggered by COVID-19 underscores the urgent need for a comprehensive paid family leave policy to support vulnerable families. A January survey conducted by UsAgainstAlzheimer's of the Alzheimer's community found that nearly three-quarters of dementia caregivers think Congress should make paid family and medical leave a priority. Further, a March survey conducted by UsAgainstAlzheimer's of how our community has been impacted by COVID-19 found that 61% of caregivers are more concerned about their financial health and their family's finances than before the COVID-19 crisis.

We know that paid leave is an effective tool for supporting unpaid family caregivers during times of crisis. According to UsA2 research, one-half of employed dementia caregivers reported that utilization of paid leave benefits improved their emotional well-being and ability to provide quality care to a loved one. It's clear that paid leave can help alleviate the hardship of dementia care on working family caregivers. Leaving this community behind negatively impacts the financial and emotional well-being of millions of American families.

In order to have the best chance of mitigating the impact of COVID-19 on the millions of families touched by dementia and other chronic conditions, we recommend that Congress expand paid leave benefits in any future COVID-19 response legislation to cover the following populations:

- People who are caring for loved ones with a serious medical condition such as Alzheimer's or dementia who have not been quarantined or show symptoms of COVID-19.
- People whose loved one's caregiving arrangements and adult day service centers are no longer in operation due to caregiver illness (including home health aides) or closures due to COVID-19 and related quarantine recommendations or requirements.
- People who work at a company with more than 500 employees that are exempted from current paid family leave requirements.

Recommendation 2: Disaggregate and report COVID-19 data by race, ethnicity, language, gender and socioeconomic status.

Despite its importance to improving our nation's ability to respond to COVID-19 in hard-hit communities, federal reporting on COVID-19 testing and mortality by race and ethnicity has been weak and inconsistent. Race and ethnicity data are missing or unspecified for nearly two-thirds (65 percent) of the CDC-reported cases of COVID-19, limiting understanding of the true impacts by race and ethnicity. The brunt of the disease is still not known among low income, limited-English-speaking populations that may not have access to timely, accurate information. Furthermore, the CDC indicates that some people with disabilities may have a higher risk of infection or severe illness because of an underlying medical condition.

On May 8, 2020, CMS issued an Interim Final Rule for public comment updating Requirements for Notification of Confirmed and Suspected COVID-19 Cases Among Residents and Staff in Nursing Homes. Section 483.80 requires nursing home facilities to:

(g)(1) Electronically report information about COVID-19 in a standardized format specified by the Secretary. This report must include but is not limited to—

- (i) Suspected and confirmed COVID-19 infections among residents and staff, including residents previously treated for COVID-19;*
- (ii) Total deaths and COVID-19 deaths among residents and staff;*
- (iii) Personal protective equipment and hand hygiene supplies in the facility;*
- (iv) Ventilator capacity and supplies in the facility;*
- (v) Resident beds and census;*
- (vi) Access to COVID-19 testing while the resident is in the facility;*
- (vii) Staffing shortages; and*
- (viii) Other information specified by the Secretary.*

A key omission from this reporting requirement is the uniform and universal collection and reporting of COVID-19 data by race, ethnicity, language, gender and socioeconomic status. This rule must be updated to adhere to new guidance issued by the Department of Health and Human Services that requires laboratories to collect demographic data like race, ethnicity, and sex when reporting test results that will go into effect on August 1, 2020. Requiring nursing homes to adhere to this guidance will improve the quality of life and health outcomes of dementia patients from racial and ethnic minority groups receiving care in a nursing home setting

A *New York Times* analysis shows that COVID-19 cases are especially high in nursing homes with large numbers of Black and Latino residents. Nursing homes where Latinos and Blacks make up a significant portion of the residents — no matter their location, size, or government rating — have been twice as likely to get hit by the coronavirus as those where the population is overwhelmingly white. Further, more than 60 percent of nursing homes where at least a quarter of the residents are Black or Latino have reported at least one coronavirus case. That is double the rate of homes where Black and Latino people make up less than 5 percent of the population.

Given the disproportionate impact of Alzheimer's and related dementias on communities of color and women, we encourage Congress hold the Department of Health and Human Services accountable for collecting and reporting comprehensive, demographic data on race/ethnicity and language of patients being tested, the rate of positive test results, and outcomes for those with COVID-19. This data will be invaluable to ensuring that our nation's health response to the current crisis is equitable and reaching all communities.

Together, these two recommendations will help us better support the economic security of families, understand the effect COVID-19 is having on communities of color and women, and identify approaches that can be taken to mitigate its devastating impact.

We appreciate the opportunity to submit these comments, and we thank you in advance for considering our recommendations. We hope our testimony will be helpful to the Committee and to individual Members of the House as Congress addresses COVID-19 issues in the weeks and months ahead. Please let us know if UsAgainstAlzheimer's can be of assistance as you continue developing strategies to address the impacts of the COVID-19 pandemic on communities of color and the nation.

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