

November 13, 2024

Dr. Mandy K. Cohen  
Director, Centers for Disease Control and Prevention  
1600 Clifton Road, Atlanta, GA 30329-4027

Dear Dr. Cohen,

We are writing to express our deep concern about the lack of urgent and intentional focus on populations that are at the highest risk of developing Alzheimer's disease and related dementias, including Black, Latino, and Indigenous people and people with intellectual and developmental disabilities in the recently forecasted funding opportunity announced by CDC's Healthy Aging Program.

Congress specifically encouraged CDC in its 2025 report language to increase capacity and focus on communities with a disproportionate burden of Alzheimer's disease - "...The Committee encourages CDC to increase capacity to support populations with a high burden of Alzheimer's and other dementias through public health promotion and workforce development." [cite, page 72]. And yet, CDC's forecasted Notice of Funding Opportunity (NOFO) for Healthy Aging fails to include specific accountable focus and funding for work with these groups.

CDC's current NOFO (CDC-RFA-DP20-2003) funds "organizations that support populations with a high burden of ADRD." This focus on at-risk populations has been excluded from CDC's forecasted NOFO (CDC-RFA-DP-25-0014) for Healthy Aging. The forecasted NOFO overlooks these often-marginalized populations—Black, Latino, Indigenous, and people with intellectual and developmental disabilities, among others. Eliminating the inclusion of a specific focus on marginalized communities goes against Congress's intent and CDC's efforts to obtain equitable and culturally-tailored public health programs.

It is well-documented that Black Americans and Indigenous people are at least twice as likely, and Hispanic Americans at least one and a half times as likely, to develop dementia as non-Hispanic Whites. Also, adults with Down syndrome – a significant portion of adults with intellectual disabilities – are at significant risk for expressing Alzheimer's related dementia by their early fifties. These well-founded facts underscore the necessity of focusing on and intentionally including Black, Latino, and Indigenous people, and people with intellectual and developmental disabilities in pursuit of health equity, especially when it comes to dementia prevention and risk reduction, early detection and management of dementia, and dementia caregiving.

We have significant concerns about the capacity, expertise, and ability of newly redirected NOFO Components to address the complex challenges facing at-risk and underserved populations who remain at the margins of public health programs. The issues faced by various cultural and ethnic groups, such as Blacks, Latinos, and Indigenous Americans, and adults with intellectual and developmental disabilities, are multifaceted and these populations require tailored strategies and specialized expertise to ensure effective brain health and dementia care initiatives.

Prevention and mitigation of Alzheimer’s disease is not only of national importance to our healthcare system but also to the millions of people living with the disease, along with their families, caregivers, and supports. The National Alzheimer’s Project Act (NAPA) specifically calls for strategies to address inequities in risk factors for Alzheimer’s disease among marginalized populations and we must remain steadfast in this commitment. The adoption of NAPA Goal 6: “Accelerate Action to Promote Healthy Aging and Reduce the Risk Factors for ADRD (Alzheimer’s Disease and Related Dementias)” is a call to action to do better on this front. We are determined to see it accomplished—starting with those on the front lines.

To address these concerns, we respectfully suggest that the NOFO be amended to dedicate a portion of the funds that Congress has appropriated to agreements with entities that are focused on reaching and helping these underserved groups. Either reinstate/continue the grant components (“Component B”) that did this in the past, or identify a new, additional Center of Excellence focused on populations with disparities related to brain health.

We believe these actions will help ensure that underserved populations receive the attention and resources they deserve as part of our national Alzheimer’s prevention strategy. Thank you for your time and consideration. We look forward to working with CDC and other stakeholders to achieve health equity for all populations at risk of Alzheimer’s disease and related dementias.

Sincerely,

National Alliance for Direct Support Professionals, Inc.

AADMD - American Academy of Developmental Medicine & Dentistry

CQL

Developmental Disabilities Nurses Association

Golisano Institute for Developmental Disability Nursing, St. John Fisher University

HealthMatters™ Program, University of Illinois Chicago

International Association for Indigenous Aging

National Alliance for Direct Support Professionals, Inc.

National Association of Hispanic Nurses

National Black Nurses Association

National Task Group on Intellectual Disabilities and Dementia Practices

The National Down Syndrome Society

UsAgainstAlzheimer’s

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CC: Dr. Karen Hacker, Director, National Center for Chronic Disease Prevention and Health Promotion