

ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE, AND SERVICES

Public Comments from Advisory Council Meeting, October 2024

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R. Eppes | 10-21-2024

On behalf of the International Association for Indigenous Aging or IA2, I'm here today to highlight the need for dedicated focus to underserved populations at greatest risk of developing Alzheimer's Disease and dementia. Over 4 years ago, the CDC Healthy Brain Initiative recognized that there were populations of U.S. Citizens that were at greater risk for Dementia and Alzheimer's Disease, these populations included Blacks, Hispanics, those with Intellectual and Developmental Disabilities and the populations we at IA2 work with on a daily basis, American Indians, Alaskan Natives and Hawaiian Natives. This diverse group of people are truly the First Americans. Three organizations were chosen as part of Component B to guide the work directly with these populations. I wish I could tell you that this solved all the problems, it did not. I wish I could say that these populations are now on even footing with White Americans, they are not. What I can tell you is that there has been progress made. For the First Americans, there is now a Roadmap for public health agencies to use to support discussion about dementia and caregiving in these communities with a 2nd version due to come out soon. There is a Social Media Toolkit to provide guidance to these agencies on best practices when communicating about brain health. Perhaps best of all, there are real conversations taking place among health professionals and families in these Pueblos, Tribes and Nations. There is no word for Dementia in many indigenous languages. This language gap is but one challenge.

And now, with the advanced NOFO recently released by the CDC, there are no longer dedicated resource centers for these high-risk populations. This is concerning especially as the recent NAPA Reauthorization added a representative from historically

underserved populations to the Advisory Council. The reason there is a need for special focus on these populations was because for decades they had been ignored or at best given lower standards of treatment. A 5 year focus does not undo the decades of mistreatment. Removing this focus puts these populations right back to where they were 5 years ago, underserved and ignored. The gains achieved will also soon be forgotten. IA2 urges this Advisory Committee, in recognition of the work of the National Alzheimer's Project Act and its reauthorization to address this issue in its advice and guidance and continue the momentum that has been started and build upon these resource centers for underserved, high risk populations.

A. Fedewa | 10-21-2024

Good afternoon, everyone. Thank you all for being here today and for this opportunity to provide a public comment. I am the Senior Manager of Government Relations at the National Down Syndrome Society (NDSS). Today I have the privilege of celebrating alongside you as several critical pieces of legislation have been signed into law--the NAPA Reauthorization Act and the Alzheimer's Investment and Accountability Act. NDSS had been an enthusiastic supporter of both pieces of critical legislation, but I would like to focus my time on the NAPA Reauthorization Act which, as enacted, includes amendments that more explicitly and robustly include the Down syndrome community in the work of this council and subsequently of the National Alzheimer's Plan.

As you all are well aware, research supports how devastatingly and disproportionately this disease impacts individuals with Down syndrome. Nonetheless, for years the Down syndrome community has been excluded from conversations, clinical trials, coverage determinations, and efforts to better understand and fight this terrible disease. The recent work of this council and the passage of the NAPA Reauthorization marks a significant evolution in this historical underrepresentation. In September, this council finalized your 2024 recommendations which included unprecedented inclusion of the Down syndrome community who were explicitly mentioned over a dozen times in the final recommendations. On the heels of this monumental progress came the passage of the NAPA Reauthorization which includes language that explicitly includes the Down syndrome community as an underserved population and creates a seat on the council for "1 representative from a historically underserved population whose lifetime risk for developing Alzheimer's is markedly higher than that of other populations." We believe a representative from the Down syndrome community is well poised to hold this seat and contribute to the valuable work of this council. We hope that when the time comes to appoint this seat, a representative nominated by the Down syndrome community will be invited to join the council.

The progress this council and the United States Congress has made gives us great hope. My work at NDSS is personal to me as I have many friends, former classmates, and close family friends with Down syndrome. While I will never truly understand what it

is like to be a parent or a sibling of someone whose life is changed by this disease, I do have the perspective of someone who never wants to see their childhood best friend or their college classmate who once shone so brightly have their light dimmed by this disease. Thank you for giving me and our entire community hope that these bright lights can keep shining. While we celebrate this great progress, I think we can all agree there is still so much work to be done. NDSS and the Down syndrome community look forward to continuing this important work alongside you all. Thank you.

M. Janicki | 10-15-2024

I am an Associate Research Professor at the Institute of Disability and Human Development at the University of Illinois Chicago, the co-President of the National Task Group on Intellectual Disabilities and Dementia Practices (NTG)--a national nonprofit advocating for adults with intellectual disabilities living with dementia, their caregivers, and families--and an alumnus of the NAPA Council. I am speaking today on the one-year anniversary of cycling off the Council to address two points that I believe should be considered as the Council prepares the 2025 Update of the National Plan.

First, on behalf of the NTG, I would like to extend our congratulations for the passage of the NAPA Reauthorization Act, recently signed into law by President Biden. This act will extend the work of the Federal Council through 2035. We are particularly pleased with the inclusion of a requirement to ensure that ethnic and racial populations and other underserved groups, including individuals with developmental disabilities such as Down syndrome--who are at higher risk for Alzheimer's or are less likely to receive care--are included in clinical, research, and service efforts to reduce health disparities in Alzheimer's. Additionally, the act requires the addition of a representative from a historically underserved population with a significantly higher lifetime risk of developing Alzheimer's. We hope this leads to the appointment of a representative of the Down syndrome community to the Council. These additions should ensure that the needs of adults with intellectual and developmental disabilities--including those with Down syndrome--will continue to be addressed in the Plan's priorities and recommendations, as they have been during my time on the Council.

The NTG's first point is our commendation of the CMS's CMMI team for their work on the new GUIDE Model program. We are pleased that 390 providers across the United States will be participating in this innovative eight-year program. The NTG recently received a grant from the Special Olympics organization to support training, education, and technical assistance aimed at increasing the inclusion of beneficiaries with intellectual disability living with dementia and their caregivers within Participant caseloads. We appreciate the CMMI GUIDE team's responsiveness to our efforts to develop educational programs for GUIDE Navigators, Practitioners, and Partners. Our goal is to promote the inclusion of beneficiaries with intellectual disabilities and to improve their access to responsive health and social care for dementia. As many adults with Down syndrome--a group at high risk for Alzheimer's and which often shows onset

of dementia in their 50s--are Medicare and Medicaid beneficiaries, we hope GUIDE Participants will consider their needs when seeking beneficiaries and delivering services. We ask the Council to prioritize this group with younger-onset dementia in the National Plan Update recommendations related to use of GUIDE Model services.

The NTG's second point concerns the recent advanced NOFO (Notice of Funding Opportunities; *Public Health Strategies to Address Alzheimer's Disease and Related Dementias: The National Healthy Brain Initiative, BOLD Public Health Centers of Excellence, and Public Health Adoption Accelerator*) issued by the CDC for extending the BOLD Act's programs' impact in the United States.^{i,ii} As you may know, the initial phase of this program will end in 2025, including the 'Components A and B' and the BOLD Centers of Excellence. Over the past four years, these components have made significant strides in raising awareness and addressing dementia among underserved populations. The 'Component Bs' have been particularly effective in addressing disparities across ethnic and cultural communities, Indigenous Americans, and adults with intellectual and developmental disabilities. Given that the NAPA Reauthorization Act specifically alludes to underserved groups, it is disconcerting that the CDC's new NOFO does not include continuation funding for initiatives targeting them. While the NOFO mentions attending to "*populations at risk for or high incidence of ADRD,*" it disaggregates responsibility and subsumes accountability for vague activities addressing these risk populations to other broadly charged Components, ensuring the loss of expertise and focus that has prevailed during the current funding period. While the Council does not set policy for Federal partners, we ask that the Council address this omission in any statements or guidance to the CDC in advocating for the continued inclusion of support for these populations. The BOLD program has been a key partner to the Council's work, and we hope that the CDC reconsiders the NOFO's structure and reinstates funding for these much-needed efforts that would lead to reduced disparities in dementia awareness and services for these populations at risk of dementia.

Thank you for the opportunity to share our thoughts, and we look forward to the Council's continued support for the inclusion of issues relevant to the intellectual disabilities and Down syndrome communities in the National Plan.

NOTES:

- i. Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (P.L. 115-406).
- ii. Description: Alzheimer's disease, the most common form of dementia, is a progressive disease that begins with mild memory loss and may lead to the inability to carry on conversations and respond to one's environment. The prevalence of Alzheimer's disease is rising with the aging of the U.S. population. In 2021, Alzheimer's disease was the fifth leading cause of death for people aged 65 years or older in the U.S., as well as the seventh leading cause of death overall. Death rates continue to rise. The CDC Alzheimer's Disease Program, through the National Healthy Brain Initiative (HBI) and its funded partners (CDC-RFA-DP20-2003, CDC-RFA-DP20-2005, CDC-RFA-DP23-0010, and CDC-RFA-PW24-0080), provides data and information to promote brain health, address

cognitive impairment, and meet the needs of caregivers through systemic and policy-driven action. This funding opportunity aligns with actions described in the Healthy Brain Initiative Road Map series, including the State and Local Road Map for Public Health: 2023-2027 and the Road Map for Indian Country. This opportunity will fund selected organizations to build the evidence base and translate research into practice that will be adopted and used across the nation. This includes helping state, tribal, local, and territorial (STLT) public health agencies--including BOLD public health programs--to implement the Road Map Series and fulfill the aim of the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (P.L. 115-406). This NOFO will consist of three components to accomplish these goals. Component 1: The National Healthy Brain Initiative--The purpose of Component 1 is to fund one organization to develop and implement public health strategies guided by the National Healthy Brain Initiative (HBI) Road Map Series. The HBI Road Map Series advances brain health as an integral component of public health. It does this through an action agenda, outlining how public health agencies and their partners can prepare all communities to act quickly and strategically by stimulating changes in policies, systems, and environments. To achieve this, the funded organization will: Develop evidence-informed training materials for current and future health care and public health professionals about the importance of ADRD and caregiving. Increase the availability and use of public health surveillance information to address cognitive impairment, cognitive decline, and caregiver support, including helping to adopt and revise the Behavioral Risk Factor Surveillance System (BRFSS) cognitive decline and caregiver optional modules. Lead and facilitate the coordination of other recipients funded under this cooperative agreement, along with national partners funded by the CDC Alzheimer's Disease Program, to address ADRD. Component 2: BOLD Public Health Centers of Excellence--The purpose of Component 2 is to fund three Public Health Centers of Excellence that will specialize in one of three topic-specific areas: dementia risk reduction, early detection and management of dementia, or dementia caregiving. Only one Public Health Center of Excellence will be funded for each topic-specific area. These funded centers will: Support and determine the needs of BOLD public health programs and other public health agencies. Identify, disseminate, and promote best practices. Translate promising research findings into useful tools and resources for the practice field. Increase professional education in ADRD. Develop and adapt materials for use by populations at risk for or high incidence of ADRD, including addressing health disparities. The funded centers will provide expert guidance and technical assistance to BOLD public health programs to build public health capacity and collaborate with national experts to make sure evidence-informed practices for their topic areas are available, disseminated, adopted, and evaluated. Component 3: ADRD Public Health Adoption Accelerator--The purpose of Component 3 is to fund up to two organizations to serve as public health strategy adoption accelerator programs. This means using dissemination and implementation science to spread and put into practice effective public health strategies, tools, and resources to tackle ADRD. The funded organization will:

Work closely with CDC staff and those working on other components of this announcement to create a prioritized list of ADRD approaches and strategies. High priority approaches and strategies will include those that have the greatest likelihood of health impact, are most ready to be scaled-up, and meet the needs of populations at highest risk for ADRD. Use proven strategies to engage partners, health care organizations, and policy makers on a national scale to enhance uptake and implementation, accelerating the impact of ADRD efforts. Advise and partner with the Component 1 and 2 recipients of this NOFO, including to provide technical assistance to help promote and disseminate their work for maximum impact across all components. Applicants can apply for more than one component but must submit a separate application for each component. The funding range per applicant per budget period for Component 1 is \$2,500,000 to \$3,000,000; Component 2 is \$750,000 to \$1,000,000; and Component 3 is \$750,000 to \$1,200,000.
