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August 14, 2024

The Honorable Cathy McMorris Rodgers Chair Committee on Energy and Commerce United States House of Representatives Washington, DC 20515

## RE: House Committee on Energy & Commerce Framework for Discussion on Reforming the National Institutes of Health (NIH)

Dear Chair McMorris Rodgers:

The American Geriatrics Society (AGS) is pleased to submit feedback on the "Reforming the National Institutes of Health Framework for Discussion" (Framework).<sup>1</sup> We particularly appreciate its focus on ensuring that the NIH is well-positioned to continue to be the worldwide leader in scientific discovery and improving the health and well-being of all Americans as we age. We also appreciate that the intention is to catalyze a discussion of where we might improve NIH efficiency and operations across the Institutes and Centers (ICs).

AGS is a nationwide not-for-profit organization dedicated to improving the health, independence, and quality of life of older people. Our 6000+ members include geriatricians, geriatrics nurse practitioners, social workers, family practitioners, physician associates, pharmacists, and internists who are pioneers in advanced-illness care for older individuals, with a focus on championing interprofessional teams, eliciting personal care goals, and treating older people as whole persons. AGS believes in a just society, one where we all are supported by and able to contribute to communities where ageism, ableism, classism, homophobia, racism, sexism, xenophobia, and other forms of bias and discrimination no longer impact healthcare access, quality, and outcomes for older adults and their care partners. AGS advocates for policies and programs that support the health, independence, and quality of life of all of us as we age.

AGS agrees that it is important and appropriate to periodically reevaluate national strategies and priorities to ensure the United States remains a leader in innovation and relevant discovery, particularly in health-oriented research, given the critical significance to the entire population as well as the fast-paced and advancing nature of science and technology. We agree with the Committee's emphasis on health, function, and independence of Americans across the lifespan at the NIH. We have focused these comments on the following:

• Establishing an independent commission to review the NIH and make recommendations to Congress.

<sup>&</sup>lt;sup>1</sup> US House of Representatives Committee on Energy & Commerce. Reforming the National Institutes of Health: Framework for Discussion. June 2024. Accessed August 9, 2024. https://dldth6e84htgma.cloudfront.net/NIH\_Reform\_Report\_f6bbdca821.pdf

- The importance of the National Institute on Aging (NIA) with its whole person focus and emphasis on cutting edge transformational research into varied chronic diseases of aging, including Alzheimer's disease and related dementias (ADRD), in shifting the NIH to a perspective that is focused on health, function, and independence of all Americans across the lifespan.
- Using congressional oversight to ensure that there is an appropriate review and evaluation of IC Directors.

## **Establishing an Independent Commission**

AGS believes that there has not been sufficient input from the scientific community to inform the proposed Framework. Absent this input, we will not achieve the shift from a disease-specific siloed approach to a holistic lifespan approach that is articulated as a primary goal of this Framework. Further, the proposal would significantly slow the progress that is being made by existing NIH ICs in increasing our understanding of the diseases and disorders of all Americans across the lifespan<sup>2</sup> and improving the healthspan of the American public.

In light of that, we strongly support the first recommendation in the proposed Framework that calls for Congress to establish a commission to lead and conduct a comprehensive review of the NIH with clear actionable recommendations for any improvements that it finds are needed. In establishing such a commission, we strongly urge Congress to ensure that:

- 1. The commission is independent by housing it within a body, such as the National Academies of Science, Engineering, and Medicine (NASEM), that has a strong record of advising Congress and the Administration on matters related to science and ensuring the health of the American public.
- 2. Input is sought from the broader scientific community, Directors of all NIH ICs, the American public, and organizations with expertise in scientific research.
- 3. The membership of the commission is inclusive of respected scientific experts, particularly those who have championed a whole person approach to research, are well-versed in multiple chronic conditions, and who have focused their work across the lifespan.
- 4. The commission is inclusive of experts who have a working knowledge of the true cost of the medical research infrastructure.

While AGS agrees that facilities and administrative costs should be justified and spending accountability is needed for indirect costs, we believe it is imperative that an independent commission receives input from multiple experts with working knowledge of the true cost of medical research infrastructure. The consequences of uninformed decision-making or across-the-board capping of indirect costs could be long-lasting and catastrophic for our country's worldwide leadership of scientific discovery.

## The Importance of the NIA to Foster a Whole Person Approach Across All Institutes

The NIA, with its whole person approach to the diseases and disorders of aging, has been at the forefront of the incredible progress that has been made in improving our collective healthspan (i.e., the portion of our lives spent in good health). That progress has been thanks, in large part, to the foresight of Congress in establishing an Institute that would take a whole person perspective and work towards a healthier future for all of us as we age. Dr. Robert Butler, the first Director of NIA, highlighted NIA's

<sup>&</sup>lt;sup>2</sup> National Institutes of Health. Revision: NIH Policy and Guidelines on the Inclusion of Individuals Across the Lifespan as Participants in Research Involving Human Subjects. December 19, 2017. Accessed August 6, 2024. https://grants.nih.gov/grants/guide/notice-files/NOT-OD-18-116.html

unique mission stating, "In the words of Congress, 'The National Institute on Aging was established for the conduct and support of biomedical, social, and behavioral research and training related to the aging process and diseases and other special problems and needs of the aged.' Congress demonstrated foresight when it placed this Institute within the National Institutes of Health, enabling it to share in the NIH's history, experience, and recognized excellence. The Institute finds itself different from most of the eleven Institutes and four Divisions of the National Institutes of Health. Its mandate reflects the concept that the study of aging is not just the study of decline, loss, and decrement — which do indeed accompany aging — and not just the study of disabilities or diseases which may in part be due to social adversities. Rather, it is also the study of the normal processes of development which are fundamental to life and about which we know all too little, including creativity, life experience, perspective, and judgment. Indeed, a major overall objective of research is to examine the variety of factors — biologic, social and psychologic — which constitute the aging process, and to translate this knowledge into ways of preventing, promoting, modifying, or reversing these various factors so that life is better and more dignified in the later years."<sup>3</sup>

Research funded by the NIA has improved clinical care of older adults across healthcare settings – contributing to our collective health, independence, and quality of life as we age.<sup>4,5,6</sup> Chronic diseases related to aging, such as diabetes, heart disease, and cancer continue to afflict 80 percent of people 65 and older.<sup>7</sup> Further, the nearly 40 percent of Medicare beneficiaries who have four or more chronic conditions account for more than 75 percent of Medicare expenditures.<sup>8</sup> Interventions from NIA-funded research have helped to reduce declines in function and susceptibility to disease or frailty and in turn delayed the onset of costly age-related diseases. Because of the NIA, the U.S. is a world leader in aging research.

The NIA supports research that impacts the health of older adults and extends far beyond dementia including the biology of aging, geroscience (study of biological mechanisms that drive aging and disease and may contribute to longevity), multiple chronic conditions, aging across the lifespan, functional status and independence, disability, polypharmacy, delirium, falls, frailty, resilience, chronic wounds, behavioral, psychological, social and economic aspects of aging, and more. There are profoundly different health issues for advanced older age than for the general population of older adults.

AGS believes that the proposed change in the Framework (as shown in Figure 1) that would eliminate the NIA and replace it with a National Institute on Dementia will undermine the ability of NIH and the nation as a whole to respond to new and multifaceted challenges affecting the health of all Americans, while also jeopardizing U.S. leadership and competitiveness in aging research. The mission of the NIA has

<sup>&</sup>lt;sup>3</sup> Butler RN. Mission of the National Institute on Aging. *J Am Geriatr Soc.* 1977;25(3):97-103. doi:<u>10.1111/j.1532-5415.1977.tb00270.x</u>

<sup>&</sup>lt;sup>4</sup> Kelley A, Addie S, Carrington-Lawrence S, et al. National Institute on Aging's 50<sup>th</sup> anniversary: advancing aging research and the health and well-being of older adults. *J Am Geriatr Soc.* 2024;72(5):1574-1582. doi:10.1111/jgs.18837

<sup>&</sup>lt;sup>5</sup> Butler MJ, Davidson KW, Suls J. The National Institute on Aging Edward R. Roybal Centers: past, present, and future of research to foster healthy aging. *J Am Geriatr Soc.* 2024;72(5):1590-1594. doi:<u>10.1111/jgs.18865</u> <sup>6</sup> Nagy CL, Bernard MA, Hodes RJ. National Institute on Aging at middle age—its past, present, and future. *J Am Geriatr Soc.* 2012;60(6):1165-1169. doi:<u>10.1111/j.1532-5415.2012.03994.x</u>

<sup>&</sup>lt;sup>7</sup> National Prevention Council. Healthy Aging in Action: Advancing the National Prevention Strategy. November 2016. Accessed August 5, 2024. https://www.cdc.gov/aging/pdf/healthy-aging-in-action508.pdf. (Page 11)

<sup>&</sup>lt;sup>8</sup> Centers for Medicare and Medicaid Services. Chronic conditions charts: 2018. 2021. Accessed August 5, 2024. <u>https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-</u> <u>Conditions/Downloads/cc\_charts.zip</u>

never been brighter or more vitally important.<sup>9,10</sup> Recent technical advances enable new aging research, including better molecular tools, data science to model the complexity and systems science inherent to aging, and real-world data opportunities to ensure access to older people that were previously difficult to study in trials. Given these advances and as the aging population increases, a critical emphasis area of any restructured NIH must be research in aging and therefore a crucial need to maintain the NIA.

Geriatricians and other geriatrics health professionals that care for older adults with complicated medical issues and social challenges strongly support a holistic life stage approach to all research that is vital to fully understand the diverse effects of aging on the older adult population and effectively address the multifaceted issues related to aging. NIA has been an effective steward of ADRD funding, including working to ensure that brain health is not siloed under a single portfolio but considered across the research that NIA and other ICs support. The reality is that more than 95 percent of Medicare beneficiaries who have AD and other dementias also have other chronic conditions.<sup>11</sup> Without consideration of these other key facets of health, we will be doing a disservice to older Americans living with dementia and other chronic conditions.

Historically, because the NIA has taken a whole person perspective on biomedical research, the NIA has been able not only to advance discoveries that can prevent or delay the onset of diseases, conditions, and functional decline associated with growing older, but also to identify factors throughout the life course that can promote healthy aging and enable us to remain independent throughout most, if not all, of our lives. AGS believes that a robust and vital NIA, with its historic whole-person focus on health, quality of life, and independence, is important to improving our collective health and well-being across the lifespan.

## Term Limits for IC Leadership

AGS is concerned that the proposed mandatory term limits for IC leadership would remove effective leaders based on a calendar rather than performance which could destabilize strong ICs. This would negatively impact the mission of NIH, health of Americans, and our country's economy and position of global leadership in research. Similar to the private sector, we recommend that the Committees of jurisdiction use oversight authority to ensure that NIH leadership have periodic performance reviews of the Directors of all NIH ICs by the NIH Director. Such reviews and opportunities for the NIH Director to consider new leadership are critical.

We appreciate the opportunity to provide these comments. If you have any questions or would like to discuss our feedback, we would be pleased to do so. Please contact Anna Kim

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<sup>&</sup>lt;sup>9</sup> Newman JC, Al-Naggar IM, Kuchel GA. Role of the National Institute on Aging in transforming aging research through geroscience and gerotherapeutics—50 years of innovation. *JAMA Intern Med.* Published online August 5, 2024. doi:10.1001/jamainternmed.2024.2534

<sup>&</sup>lt;sup>10</sup> Covinsky KE, Mody L, Inouye SK. Why do we (and still do!) need the National Institute on Aging—50 years of innovation. *JAMA Intern Med.* Published online August 5, 2024. doi:<u>10.1001/jamainternmed.2024.1326</u>

<sup>&</sup>lt;sup>11</sup> Alzheimer's Association. Alzheimer's and Multiple Chronic Conditions Fact Sheet. March 2022. Accessed August 6, 2024. https://www.alz.org/media/Documents/alzheimers-and-multiple-chronic-conditions.pdf

(<u>akim@americangeriatrics.org</u>). We look forward to providing input to the Commission that is proposed in recommendation one.

Sincerely,

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