

August 16, 2024

The Honorable Cathy McMorris Rodgers Chair Committee on Energy and Commerce 2125 Rayburn House Office Building Washington, DC 20515

Dear Chair McMorris Rodgers:

On behalf of the American Speech-Language-Hearing Association (ASHA), I write to provide feedback on the framework for discussion, "Reforming the National Institutes of Health." ASHA appreciates the opportunity to provide feedback to the Committee because we want to ensure that the research supported by the National Institutes of Health (NIH) fulfills the agency's mission to acquire new knowledge that helps prevent, detect, diagnose, and treat diseases and disabilities, which will ultimately help Americans live longer and healthier lives.

ASHA is the national professional, scientific, and credentialing association for 234,000 members, certificate holders, and affiliates who are audiologists; speech-language pathologists (SLPs); speech, language, and hearing scientists; audiology and speech-language pathology assistants; and students. Audiologists specialize in preventing and assessing hearing and balance disorders as well as providing audiologic treatment, including hearing aids. SLPs identify, assess, and treat speech, language, swallowing, and cognitive communication disorders.

While we support enhancing the effectiveness and efficiency of NIH, we believe that any restructuring must preserve the crucial role of the National Institute on Deafness and Other Communication Disorders (NIDCD) to advance understanding of normal and disordered processes of hearing, balance, voice, speech, and language.

The discussion framework proposes to merge NIDCD with the National Institute of Child Health and Human Development (NICHD) to form a newly conceived National Institute for Disability Related Research. Although the framework suggests a budget increase of \$24 million toward this new Institute, ASHA is concerned with the potential loss of focus on important priorities for NIDCD. NIDCD develops its priorities through an iterative and transparent process that engages industry, patient and consumer groups, professional organizations, government partners, and the scientific community. NIDCD's priorities and strategic plan reflect goals that will further scientific advances and accelerate promising treatments for people with hearing loss or communication disorders. NIDCD-funded research supports a broad range of research that addresses both disabilities and normal processes related to hearing, balance, speech, language, and cognitive communication. In addition, NIDCD's portfolio is not limited to pediatric research. Just as audiologists and SLPs treat patients across the entire human lifespan, NIDCD funds research in its priority areas with the aim of improving health and quality of life from birth to end of life.¹

NIDCD funds critical research addressing medical and behavioral pathologies affecting people with communication impairments and disorders and supports the development of devices that assist individuals with hearing loss and other communication disorders. These disorders affect the health and well-being of millions of Americans and impact the economy through lost

productivity; the increased need for services and supports to ensure appropriate public education for students with disabilities; greater rehabilitation needs; higher health care expenditures; and lost revenue.

The impact of hearing loss adversely affects our most basic human right: communication. Hearing loss is currently the third-leading chronic health condition in the United States, and it's rapidly increasing. About one in three adults over 65 and nearly half of adults 75 and older have hearing loss.² In 2020, 6,000 infants were identified with a permanent hearing loss. In addition, tens of thousands of children are exposed to infections during pregnancy, such as cytomegalovirus, that carry significant risk of causing hearing loss as those children grow.³ Hearing loss impacts are felt across populations, from newborns and young children to older adults. Hearing loss disproportionately impacts groups such as military veterans and those exposed to occupational or recreational noise. Hearing loss is associated with increased risks of social isolation, depression, and cognitive decline.⁴

Since its establishment in 1988, NIDCD has been instrumental in funding groundbreaking research that has had a profound impact on millions of Americans. Some of the notable research areas funded by NIDCD include:

- 1. Hearing Loss and Hearing Aids: Funding from NIDCD is helping to support improvements in hearing aid technology, with research projects focused on enhancing the way that hearing aids process speech to improve understanding for the user. NIDCD-funded researchers are also seeking ways to reduce noise interference and feedback and to develop better microphones for hearing aids, all in an effort to allow hearing aid users to better understand speech.⁵
- 2. Speech and Language Development in Children: NIDCD-funded research has provided critical insights into how children acquire speech and language skills, leading to the development of effective interventions for children with speech and language disorders. This research is essential for early diagnosis and treatment, which can prevent long-term communication challenges. Ongoing NIDCD-funded research in this area includes gathering data to establish reliable signs and symptoms for specific speech disorders in children, which can then be used to develop accurate diagnostic tests; convening experts to address the lack of standard assessments and effective treatments for autistic children; and exploring the role of genetic factors linked to communication disorders.⁶
- 3. **Voice Disorders**: NIDCD funds studies to further the understanding of diseases and stresses that can harm the voice and test new ways to diagnose, treat, or cure voice disorders. Current NIDCD-funded research in this area, including a project on how the brain controls the muscles and nerves that produce speech, may help clinicians and other researchers design better treatments for voice disorders.⁷
- 4. Balance Disorders: NIDCD-funded research on balance disorders, which are often linked to inner ear problems, aims to help individuals maintain their mobility and independence. Current studies supported by NIDCD are exploring ways to regrow inner-ear structures that are crucial for balance but are destroyed by aging, medications, infections, or trauma; testing prosthetic devices to regulate the function of balance organs in the inner ear; and developing novel tests to appropriately diagnose balance disorders.⁸

The research funded by NIDCD not only improves the lives of individuals with conditions diagnosed and treated by audiologists and SLPs, but also contributes to the broader scientific understanding of these complex conditions. We believe that any reforms to NIH should preserve and enhance the capabilities of NIDCD to continue its vital work. We urge the Committee to consider the unique and essential contributions of NIDCD as you move forward with your legislative proposals for NIH reform. Continued support for NIDCD is crucial for maintaining progress in understanding and treating communication, hearing, and balance disorders, which affect millions of Americans.

It is imperative that stakeholders understand specific mechanisms and congressional intent regarding the proposed restructuring and redistribution of NIH resources toward the new institutes and centers as envisioned by your reform proposal. Detailed information is crucial for ASHA to fully assess the implications of the proposed reorganization. Therefore, we urge the Committee to provide comprehensive details that reflect the intent to protect existing research funding for the priority areas of focus within the NIDCD research portfolio.

NIH has evolved over time and been shaped by bipartisan initiatives in Congress, including the passage of the National Deafness and Other Communication Disorders Act of 1988—bipartisan legislation signed into law by President Ronald Reagan that created the NIDCD. Some institutes within the NIH were created to focus on specific diseases (e.g., National Cancer Institute), some on populations (e.g., National Institute on Aging), and others on function (e.g., NIDCD). All three are needed to holistically address population health, diseases, and functions. Out of the \$47.1 billion appropriated to NIH by Congress for fiscal year 2024, NIDCD received \$534 million in funding, or just over 1% of total NIH appropriations. The importance of the research funded by this relatively small portion of NIH dollars to the patient populations served by ASHA members cannot be overstated.

NIDCD investments are needed to ensure groundbreaking research on communication sciences and disorders that enables the advancement of evidence-based assessment, diagnostics, treatment and habilitative and rehabilitative health care services provided by audiologists and SLPs. NIDCD-funded research translates into more effective and efficient health care, enhancing outcomes for audiology and speech-language pathology patients. ASHA shares the Committee's desire to ensure that the NIH operates at the highest standards and greatest potential as the nation's foremost research center. We stand ready to collaborate and provide more substantial feedback when supplemental details further describing the plans, implications, and congressional intent of your discussion framework are made available.

Thank you for the opportunity to provide feedback on the framework to reform the NIH. ASHA is committed to working with the Committee on Energy and Commerce to ensure that these legislative efforts strengthen the ability of NIDCD to fulfill its mission. If you have additional questions, please contact Josh Krantz, director of federal affairs for health care, at ikrantz@asha.org.

Sincerely,

Tena L. McNamara, AuD, CCC-A/SLP

Jos Jamaia

2024 ASHA President

² Centers for Disease Control and Prevention. (2024, May 15). *Data and Statistics About Hearing Loss in Children*. https://www.cdc.gov/hearing-loss-children/data/index.html

⁴ The Aging and Cognitive Health Evaluation in Elders Study. (September 2023). *Key Findings*. https://www.achievestudy.org/key-findings

- ⁵ National Institute on Deafness and Other Communication Disorders. (July 2015). *NIDCD Fact Sheet* | *Hearing and Balance: Hearing Aids*. https://www.nidcd.nih.gov/sites/default/files/Documents/health/hearing/nidcd-hearing-aids.pdf
 ⁶ National Institute on Deafness and Other Communication Disorders. (2022, October 13). *Speech and Language*
- Developmental Milestones. https://www.nidcd.nih.gov/health/speech-and-language
- ⁷ National Institute on Deafness and Other Communication Disorders. (2021, April 15). *Taking Care of Your Voice*. https://www.nidcd.nih.gov/health/taking-care-your-voice
- ⁸ National Institute on Deafness and Other Communication Disorders. (December 2017). *NIDCD Fact Sheet* | *Hearing and Balance: Balance Disorders*.

https://www.nidcd.nih.gov/sites/default/files/Documents/health/balance/BalanceDisorders-508.pdf

¹ National Institute on Deafness and Other Communication Disorders, Department of Health and Human Services, National Institutes of Health. (March 2024). *National Institute on Deafness and Other Communication Disorders:* Congressional Justification, FY 2025. https://www.nidcd.nih.gov/sites/default/files/2024-03/nidcd-cj-fy25.pdf

³ Centers for Disease Control and Prevention. (2024, May 10). *Congenital CMV and Hearing Loss*. https://www.cdc.gov/cytomegalovirus/congenital-infection/hearing-loss.html