



April 12, 2020

Francis S. Collins, MD, PhD
Director
National Institutes of Health
1 Center Drive
Bethesda, MD 20814

Re: Response to NIH Request for Information to Advance and Strengthen Racial Equity, Diversity, and Inclusion in the Biomedical Research Workforce and Advance Health Disparities and Health Equity Research (NOT-OD-21-066)

Dear Director Collins:

On behalf of the Disability and Rehabilitation Research Coalition (DRRC), we appreciate the opportunity to comment on the National Institutes of Health's (NIH) Request for Information on *Inviting Comments and Suggestions to Advance and Strengthen Racial Equity, Diversity, and Inclusion in the Biomedical Research Workforce and Advance Health Disparities and Health Equity Research* (NOT-OD-21-066). We applaud NIH for the launch of the UNITE Initiative. We look forward to working with you and your colleagues at NIH to continue efforts to achieve a more equitable culture within the biomedical research enterprise and to break down barriers to equity in the workforce.

The DRRC is a coalition of 26 national research, clinical, and consumer non-profit organizations committed to improving the science of rehabilitation, disability, and independent living. The DRRC seeks to maximize the return on the federal research investment in these areas with the goal of improving the ability of Americans with disabilities to live and function as independently as possible following an injury, illness, disability, or chronic condition. Addressing the health and social disparities faced by underserved populations has long been a critical focus of the DRRC.

The DRRC believes that disability and rehabilitation research play a critical role in enabling and empowering individuals with disabilities to live the American dream. Our guiding principles include a recognition that disability, like race and gender, is a natural and normal aspect of the human experience that in no way diminishes a person's right to fully participate in all aspects of life. Also, public policy should reflect and further the goals of disability policy articulated in the Americans with Disabilities Act (ADA) – equality of opportunity, full participation, independent living, and economic self-sufficiency.

PRESIDENT BIDEN'S EXECUTIVE ORDERS

We fully support President Biden's executive order on equity, diversity, and inclusion. EO 13985, *Advancing Racial Equity and Support for Underserved Communities Through the Federal Government*, defines equity as the "consistent and systematic fair, just, and impartial treatment of all individuals, including individuals who belong to underserved communities that have been denied such treatment, such as Black, Latino, and Indigenous and Native American persons, Asian Americans and Pacific Islanders and other persons of color; members of religious minorities; lesbian, gay, bisexual, transgender, and queer (LGBTQ+) persons; *persons with disabilities*; persons who live in rural areas; and persons otherwise adversely affected by persistent poverty or inequality."

We fully support the recognition that the government's goal in advancing equity is "to provide everyone with the opportunity to reach their full potential." We also support the directive that "each agency must assess whether, and to what extent, its programs and policies perpetuate systemic barriers to opportunities and benefits for people of color and other underserved groups (which includes people with disabilities)." We also agree with the assertion that "such assessments will better equip agencies to develop policies and programs that deliver resources and benefits equitably to all."

FOCUS OF THE REQUEST FOR INFORMATION (RFI)

We are pleased that the RFI is consistent with and furthers the goals and objectives of the Executive Order and includes several critical premises regarding equity at NIH:

- The ability of NIH to remain at the forefront of biomedical research and to ensure that scientific discoveries truly benefit all depends upon diverse skill sets, viewpoints, and backgrounds.
- As a global leader in biomedical research, NIH carries a weighted responsibility to address the systemic challenges and barriers affecting the NIH workforce and NIH-supported biomedical community that hinder the progress necessary to support true health equity.
- Enhancing workforce diversity and equity across the biomedical enterprise are critical steps to achieving progress.
- Ultimately NIH strives to foster a biomedical research community and an NIH workplace that are free from hostility and discrimination grounded in race, sex, or other federally protected characteristics [which includes disability].
- NIH seeks to promote research to inform and address the breadth of health disparities/inequities.

Race

We commend NIH on the establishment of the UNITE Initiative, in particular the recognition of the need to address long-standing health disparities and minority health inequities across the country and in NIH workforce, and the issuance of the RFI, which provides stakeholders with the

opportunity to comment on specified topic areas of critical importance to address systemic racism.

Disability

People with disabilities have always faced structural inequities in health (and access to health care), employment, community participation, and numerous other aspects of society. These disparities are widely recognized by the federal government, stakeholder organizations, and the general public, including within NIH's own Notice of Interest in Diversity¹, which highlights individuals with disabilities as a group "underrepresented in the biomedical, clinical, behavioral, and social sciences." Despite this broad awareness, ***people with disabilities are not designated as a U.S. health disparity population by NIH and the National Institute on Minority Health and Health Disparities (NIMHD)***, an omission that the DRRC has long sought to resolve.

Disparities faced by people with disabilities are also quite prevalent in the scientific workforce, underscoring the need for programs such as the UNITE Initiative to include the disability population. A 2019 report by the National Science Foundation found that while the proportion of undergraduate students with one or more disabilities enrolled in a science and engineering (S&E) field was similar to the proportion of those without disabilities (approximately 28% for both populations), those with disabilities were less likely to receive financial aid and less likely to be enrolled full time for a full year at one institution.² The same report found that about 10% of employed scientists and engineers report one or more disabilities. However, people with disabilities have been significantly underrepresented in the NIH workforce and the field of NIH grantees.

One recent study found that the representation of people with disabilities in the pool of NIH grant applicants and successful awardees was not only disproportionately low, but has actually declined significantly over the past decade, from 1.9% of grant applicants with a principal investigator (PI) reporting a disability in 2008 to 1.2% in 2018.³ The trend is the same for NIH awardees. Additionally, the same study demonstrated that "overall grant success rates differed by disability status (27.2% for those reporting disability vs. 29.7% in those reporting no disability)."

Intersectionality Between Race and Disability

Research indicates that there are particularly high rates of disability within racial and ethnic minority populations. Recognized health disparity populations, including African Americans, American Indians, Alaska Natives, older adults, women, residents of rural and frontier communities, and people with low incomes and/or education levels, also have significantly higher rates of disability. The intersection of minority identities, including disability, should be recognized as an overarching and critical dimension of health and health care disparities. All

¹ NOT-OD-20-031, November 22, 2019.

² National Science Foundation, National Center for Science and Engineering Statistics. 2019. *Women, Minorities, and Persons with Disabilities in Science and Engineering: 2019*. Special Report NSF 19-304. Alexandria, VA. Available at <https://www.nsf.gov/statistics/wmpd>.

³ Swenor BK, Munoz B, Meeks LM (2020). A decade of decline: Grant funding for researchers with disabilities 2008 to 2018. PLoS ONE 15(3): e0228686. <https://doi.org/10.1371/journal.pone.0228686>.

equity-focused efforts, including the NIH UNITE Initiative, should take intersectionality into account, and ensure that all minority populations are recognized, represented, and equitably served.

DRRC COMMENTS

Overarching Comment

In light of the premises of the RFI highlighted above and consistent with EO 13985's definition of equity and its focus on addressing systemic barriers affecting all underserved groups, including people with disabilities, we interpret the RFI as seeking comments related to all protected classes. **Is our assumption correct? If not, we request an opportunity to meet with you to learn more about NIH's efforts to address workforce and health care disparities affecting people with disabilities.**

Specific Recommendations

DRRC urges NIH to recognize the intersectionality between race and disability in its efforts to advance equity, diversity, and inclusion within all facets of the biomedical research workforce and expand research to eliminate or lessen health disparities and inequities. Such research can help build further understanding of the mechanisms in which disability status, racial and ethnic minority status, and other social determinants of health interact to compound health disparities and societal inequities. NIH-funded research should always be cognizant of these factors and the UNITE Initiative should encourage specifically targeted research to better understand their collective and overlapping impact.

As explained above, NIH's own Notice of Interest in Diversity highlights individuals with disabilities as a group "underrepresented in the biomedical, clinical, behavioral, and social sciences." Despite this broad awareness, people with disabilities are *not* designated as a U.S. health disparity population by NIH and the National Institute on Minority Health and Health Disparities (NIMHD). We recommend that this omission be resolved.

DRRC believes that the biomedical research workforce should more fully represent the broader population, especially those which NIH research aims to serve. We also note that 21st century research practice increasingly recognizes the importance of breaking down the division between researchers and their subjects, in order to create more equitable and meaningful research. We urge NIH to prioritize diversity, equity, and inclusion among its own workforce, its grantees, clinical trial participants, public advisors, and the stakeholder groups with which NIH engages, including individuals with disabilities.

We also ask that NIH work to adopt language stating that biomedical researchers who have similar backgrounds to the underserved groups identified in the RFI be provided equitable funding. For example, any projects researching the disparate effects of COVID-19 on the Black and African American communities should include funding for a Black or African American researcher, with similar standards for projects targeted at other underserved communities. Studies have found that lower rates of NIH R01 awards go to African American or Black

scientists than White scientists.⁴ This study controlled for education background, country of origin, training, previous research awards, and employer characteristics. Black and African American researchers deserve equitable funding, particularly when it comes to studying disparate health in similar communities.

DRRC has in the past called on all Institutes and Centers within NIH to adopt the community engagement requirements used by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) and the Patient-Centered Outcomes Research Institute (PCORI). Similar guidelines should be adopted to ensure participation and engagement from other traditionally underserved communities. It is time that many or most (if not all) research studies sponsored by NIH should include a relevant, representative, and diverse body of stakeholders in research development, data collection, analysis and interpretation, and the dissemination and utilization of research findings.

Diversity and inclusion efforts at NIH addressing training and mentorship programs among its workforce and similar programs operated by NIH grantees must include individuals with disabilities and chronic conditions. We urge NIH to develop and equitably fund pre-doctoral and post-doctoral training programs for researchers with disabilities, and to encourage grant applicants to disclose the disability status of team members. NIH should also ensure that mentorship programs supported by the Institutes are inclusive of individuals with disabling conditions, both among the mentor and mentee populations. Supporting a diverse and inclusive workforce will not only begin to combat long-existing barriers to access and inequities in the biomedical research pipeline but will lead to more responsive research and dissemination strategies and maximize the impact of NIH's critical work for all populations.

We thank you for the opportunity to comment on NIH's important and ongoing efforts to advance equity, diversity, and inclusion and improve federal health disparities and health equity research. We look forward to continuing to engage with NIH as these efforts take shape, and we hope that our collective comments will help to guide an equitable response to the mission laid out in the President's Executive Orders. If you have any questions, please contact the DRRC coordinators at Peter.Thomas@PowersLaw.com, Bobby.Silverstein@PowersLaw.com, and Joseph.Nahra@PowersLaw.com, or call 202-466-6550.

Sincerely,

The Undersigned Members of the Disability and Rehabilitation Research Coalition

American Academy of Orthotists & Prosthetists
American Academy of Physical Medicine & Rehabilitation *
American Association on Health and Disability
American Congress of Rehabilitation Medicine *
American Medical Rehabilitation Providers Association
American Music Therapy Association

⁴ Hoopé et al., *Sci. Adv.* 2019;5: eaaw7238. 9 Oct 2019.

*American Occupational Therapy Association **
*American Physical Therapy Association **
American Speech-Language-Hearing Association
American Therapeutic Recreation Association
*Association of Academic Physiatrists **
Association of Rehabilitation Nurses
*Brain Injury Association of America **
Christopher & Dana Reeve Foundation
National Association for the Advancement of Orthotics & Prosthetics
*National Association of Rehabilitation Research and Training Centers **
National Association of State Head Injury Administrators
National Multiple Sclerosis Society
National Neurotrauma Society
Paralyzed Veterans of America
Rehabilitation Engineering and Assistive Technology Society of North America
United Spinal Association

** DRRC Steering Committee member*