DRRC
Disability & Rehabilitation Research Coalition

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Via Electronic Submission on NIH RFI Website

Re: DRRC Comments on NIH-Wide Strategic Plan Framework for Diversity, Equity, Inclusion, and Accessibility

[Please include any comments on NIH's priorities across the three Objectives articulated in the Framework, including potential benefits, drawbacks or challenges, and other priority areas for consideration.]

Objective 1: Implement Organizational Practices to Center and Prioritize DEIA in the Workforce [NIH Workforce/Workforce at Institutions Supported by NIH Funding] (500-word max)

DEIA at NIH covers two distinct populations – the NIH-employed workforce and the broader scientific workforce at institutions and projects supported by NIH grants. The DRRC has previously submitted comments focused on the former population in response to the recent RFI on the COSWD strategic plan. Our comments here focus on the latter, as well as the portion of the NIH workforce that is contracted and thus not included in existing demographic and disability status reporting requirements at NIH.

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. In the Strategic Plan, we urge NIH to prioritize diversity, equity, inclusion, and accessibility among its own workforce, its grantees, clinical trial participants, public advisors, and the stakeholder groups with which NIH engages, including individuals with disabilities. NIH should explicitly include language around scientists with disabilities in the Strategic Plan.

Additionally, the Strategic Plan can and should include language directing Institutes and Centers, including sub-offices, to regularly report progress towards measuring and ameliorating systemic barriers in accessing benefits and opportunities within these agencies. Collection and reporting of data on the disability status of grant applicants, awardees, and their project staffs would be particularly useful to better understand such progress, and to identify where additional efforts to solicit and enhance diversity in the research workforce would be most effective. It would also be useful to collect and report data on disability status and other demographic factors among the NIH contract workforce, particularly scientists.

DEIA efforts at NIH addressing training and mentorship programs among its contract workforce and similar programs operated by NIH grantees must include individuals with disabilities and chronic conditions. We urge NIH to include in the Strategic Plan a goal 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 scientific 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.

Objective 2: Grow and Sustain DEIA through Structural and Cultural Change [Stewardship/Partnerships and Engagements/Accountability and Confidence/Management and Operations] (500-word max)

The DRRC fully supports the President's Executive Orders 13895 and 14035 on diversity, equity, inclusion, and accessibility, and appreciates NIH's focus on advancing DEIA within the agency. We recognize that the definition of equity in EO 13895 includes people with disabilities as an equity population and urge NIH to formally adopt this definition in its entirety throughout the Strategic Plan. The Plan must explicitly include people with disabilities as a target of DEIA efforts throughout the Plan and all initiatives within NIH, its Institutes and Centers, and grantees. People with disabilities have always faced structural inequities in health (and access to health care), employment, community participation, and numerous other aspects of society. Disparities faced by people with disabilities are also quite prevalent in the scientific workforce, underscoring the need for the DEIA Plan to include the disability population. Additional work is necessary to shed light on the extent to which people with disabilities have long been underrepresented in the NIH contract workforce and the field of NIH grantees.

NIH has undertaken numerous initiatives over the past year (and beyond) to advance DEIA in addition to the development of the Strategic Plan, including a March 2021 Request for information on advancing racial equity, diversity, and inclusion in the workforce and advancing health disparities research; the development of the next strategic plan for the Chief Office of Scientific Workforce Diversity, and the creation of the Advisory Committee to the NIH Director Working Group on Diversity (ACD WGD) Subgroup on Individuals with Disabilities. The DRRC is deeply invested in the totality of this work, but these efforts will only reach their full potential if they are viewed as complementary to each other and not siloed, individualized efforts. We urge NIH to include in the Strategic Plan a plan to ensure that leadership systematically reviews existing efforts and recommendations and works to implement them throughout the agency.

Further, NIH should consider expanding the scope of the Subgroup, or creating a new standing committee with broader authority, to focus on all disability-related issues within NIH, including celebrating the work of staff and grantees with disabilities, encouraging disclosure of disability information for reporting in grant applications and awards, and identifying additional strategies to support people with disabilities throughout NIH and the broader workforce.

Regarding accountability for DEIA-related funding programs, NIH should work with COSWD to review existing programs and ascertain the extent to which there is appropriate participation by individuals with disabilities, including with regards to goals, benchmarks, disaggregation of data by disability status, progress reports, and proactive efforts to address any disproportionate participation (or lack thereof).

Given the additional focus in Executive Order 14035 and in the Strategic Plan on "accessibility" as part of DEIA, it is incumbent for NIH to ensure that opportunities provided to individuals with disabilities are as effective and meaningful as those provided to others. The Plan should include specific initiatives and language focused on accessibility and usability of communications, including accessibility and usability of platforms, notifications, conferences, and more.

Objective 3: Advance DEIA Through Research [Workforce Research/Health Research] (500-word max)

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 social determinants of health interact to compound health disparities and societal inequities. NIH-funded research should always be cognizant of these factors and the Strategic Plan should encourage specifically targeted research to better understand their collective and overlapping impact.

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). Based on the current research into the numerous disparities faced by people with disabilities, we join the National Council on Disability and other advocacy groups in recommending that this omission be resolved. Such a designation would open new avenues for NIH to better examine and understand the broad impacts of disability beyond condition-related health status. The Department of Health and Human Services already recognizes people with disabilities as a health disparity population through the Healthy People 2030 initiative; this designation should be replicated at NIMHD and NIH should invest targeted funds into researching disability disparities as an additional focus of existing health disparities research. It is critical that these efforts be supplemental, rather than supplanting or repurposing resources devoted to other health disparities research.

We also urge NIH to adopt policies to ensure that people with disabilities and other traditionally underserved communities are also represented across the stages of NIH-conducted and -funded research. DRRC has in the past called for 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.

Finally, the COVID-19 pandemic has underscored the lack of reliable information on people with disabilities at the federal, state, and local levels. As a critical component of ensuring DEIA and addressing the disparities faced by people with disabilities, we urge NIH to work with other federal partners, including the newly formed Equitable Data Working Group, to ensure that disability status is included as a mandatory demographic component in all data collection efforts advanced through NIH. Standardizing and collecting uniform measures of disability, along with other demographic categories such as race and ethnicity, is critical and clearly necessary to improve research impacting underserved communities.