



June 3, 2022

Dr. Marie A. Bernard
Chief Officer for Scientific Diversity
National Institutes of Health
31 Center Drive
Bethesda, MD 20892

**Re: DRRC Recommendations for Implementing the COSWD Strategic Plan
from a Disability Perspective**

Dear Dr. Bernard:

On behalf of the Disability and Rehabilitation Research Coalition (DRRC)¹, we commend the National Institutes of Health (NIH) and the NIH Chief Officer for Scientific Workforce Diversity (COSWD) on the adoption of the [2022-2026 Strategic Plan](#) “Great Minds Think Differently.”

In particular, we commend COSWD for recognizing individuals with disabilities (page 10) as an underrepresented group for purposes of enhancing the diversity, equity, inclusion, and accessibility (DEIA) of the NIH intramural, extramural, and external scientific workforce, including NIH-funded institutions (page 4). In addition, we commend NIH for establishing the Advisory Committee to the Director Working Group on Diversity (ACD WGD) Subgroup on Individuals with Disabilities to identify strategies that support individuals with disabilities in the biomedical research workforce and COSWD for recognizing the need to collaborate with the Subgroup to enhance its focus on accessibility in the scientific workforce (page 17).

The purpose of this letter is to provide a series of recommendations for consideration by COSWD and the Subgroup on Individuals with Disabilities to maximize the likelihood that people with disabilities, along with other underrepresented groups, realize the goals and objectives of the NIH COSWD Strategic Plan to **BUILD, DISSEMINATE, and ACT** on evidence to effect change in the scientific workforce by fostering cultures of inclusive excellence through data-driven, collaborative, transparent, and measurable facilitators of DEIA, and by developing, testing, and continually improving programs and practices, consistent with these three goals (page 3). **We are also requesting a meeting with you and your colleagues in the coming weeks to discuss these recommendations further.**

¹ The Disability and Rehabilitation Research Coalition 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.

Our overall recommendation is that NIH make a concerted effort, directly, through contract, or other arrangement, to:

- Determine the extent to which NIH and COSWD relied on (or failed to rely on) existing disability-related scientific workforce research to accomplish strategic goals and objectives.
- Review the literature on DEIA from a disability perspective to determine whether NIH should support additional research on people with disabilities in the scientific workforce.
- Determine the extent to which existing NIH programs, projects, and activities applicable to NIH intramural, extramural, and external scientific workforce, including NIH-funded institutions, are inclusive of people with disabilities.
- Identify specific barriers and gaps in programming related to the scientific workforce facing people with disabilities.
- Identify stakeholder groups with disability-related experience and expertise with whom to collaborate in order to inform, communicate, and implement evidence-based practices and metrics.
- Identify specific strategies and tactics designed to ensure that people with disabilities are included in DEIA-related NIH programs, projects, and activities (including piloted DEIA programs), including both generic as well as disability-specific initiatives.
- Disaggregate data and establish disability-specific metrics to assess progress in efforts to achieve DEIA outcomes for scientists with disabilities.
- Monitor and adopt accountability strategies that hold individuals and entities accountable for DEIA outcomes for people with disabilities.
- Establish long-term infrastructure across NIH Institutes and Centers to facilitate and sustain progress and change across the areas included in this letter.

Our specific recommendations correspond to the organization of the COSWD Strategic Plan:

- Goal 1: Build the Evidence
- Goal 2: Disseminate the Evidence
- Goal 3: Act on the Evidence

GOAL 1: BUILD THE EVIDENCE

The first goal outlined in the Strategic Plan focuses on building the evidence to enhance DEIA in the NIH workplace by using research insights and NIH as a testbed for innovative scientific programs, including by expanding the knowledge of quality scientific research on scientific workforce DEIA issues; identifying effective DEIA programs and filling the gap in programming, and evaluating piloted DEIA programs to assess program impact (page 5; pages 16-19).

Paragraph 1 (pg. 16): Asserts that COSWD “has stayed abreast of multidisciplinary research on scientific workforce DEIA” and then discusses the COSWD expanding on evidence-based research to contribute to knowledge on scientific workforce DEIA, with a link to the diversity research articles that were referenced.

- None of the articles referenced in this link specifically address people with disabilities, especially scientists/researchers with disabilities.
- Of the 35 endnotes included in the Strategic plan, only one (footnote 20) specifically includes reference to a disability-related study on the scientific workforce (i.e., funding for researchers with disabilities). [See Swenor BK, Munoz B, and Meeks LM. [A Decade of Decline: Grant Funding for Researchers with Disabilities](#)] In addition, footnote 5 includes brief information about disability; footnote 22 references an article about increasing the number of physicians with disabilities; and footnote 25 includes a few mentions of disability. More specifically:
 - In Footnote #20, the article “[Intersectional inequalities in science](#)” (Kozlowski et al., 2022), was referenced. Disability was only mentioned once in the article, linked to an article titled “[Disabled in academia: to be or not to be, that is the question](#)” (Yerbury and Yerbury, 2021). The latter article was not available for public access but examines what it is like living with a disability and working in academic institutions.
 - Footnote #22, “[The Science and Value of Diversity: Closing the Gaps in our Understanding of Inclusion and Diversity](#)” (Swartz et al., 2019) primarily mentions disability when explaining the umbrella term of diversity but does not dive deeper into diversity in science, which is the aim of the article. However, an article referenced in the Swartz article presented valuable information, “[Removing Barriers and Facilitating Access: Increasing the Number of Physicians with Disabilities](#)” (Meeks et al., 2018).
 - Footnote #25, “[Advancing Science for the Health of Women: The Trans-NIH Strategic Plan for Women’s Health Research](#)” made only a few mentions of disability in the plan but was worth noting as it is an NIH plan that could be expanded upon.
- What steps are planned to add to the knowledge on scientific workforce DEIA issues for people with disabilities?

Paragraph 3 (pg. 16): The [Workplace Climate and Harassment Survey](#) (WCHS), which is linked here and elsewhere in the text, reports that people with disabilities (among several other groups) are more likely to be subject to sexual harassment in the workplace.

- Disability-based harassment is the number 1 complaint filed by federal employees with disabilities. [The EEO Status of Workers with Disabilities in the Federal Sector (May 2022)]
- What steps are planned to specifically recognize and address disability harassment in the federal workforce?

Paragraph 6 (pg. 16): The [NIH-wide Implicit Bias online resource](#) is linked here and elsewhere in the text.

- The NIH Implicit Bias Training mentions disability once under the umbrella term of diversity but does not include any specific disability-related scenarios, examples, or data on disability in the scientific workforce of the workforce in general.
- What steps are planned to include disability-specific scenarios, examples, and data in the implicit bias online resource?

Paragraph 7 (pg. 17): Makes reference to the [ACD WGD Subgroup on Individuals with Disabilities](#).

- How is COSWD collaborating with the Subgroup on Individuals with Disabilities to expand DEIA for scientists with disabilities?
- The Subgroup webpage references strategies, evidence-based practices, and programs that they plan to identify to support scientists with disabilities.
 - Will these strategies be shared with the public?
 - What steps have been taken and are planned to include scientists with disabilities in the Subgroup and other Subgroups (to address intersectionality)?

Through Collaborations (pg. 17): This section explains that through collaboration, COSWD will pilot programs that encourage greater inclusion across various workforce settings.

- How does the NIH intend to pilot programs/identify pilot collaborations that are disability-inclusive?

Through Accountability (pg. 17): This section explains that building valuable evidence requires strong research accountability practices and the need to work strategically with collaborators to ensure impactful accountability.

- What strategies and tactics are being planned and implemented to ensure the inclusion of people with disabilities and persons with disability-related expertise in order to ensure accountability of pilot programs for people with disabilities?

Through Evaluation (pg. 17): This section explains that program evaluation data is necessary for assessing the impact of existing programs and new pilot programs.

- What qualitative and/or quantitative data will be collected and analyzed to assess the impact of DEIA interventions for scientists with disabilities? How will COSWD address the issue of disability disclosure (i.e., overcome the administrative, institutional, and professional barriers associated with acknowledging disability)?

GOAL 2: DISSEMINATE THE EVIDENCE

The second goal outlined in the Strategic Plan addresses strategies on disseminating evidence through work with the biomedical scientific community, from trainees to established tenured scientists (page 5 and pages 20-22).

Communicating on DEIA (pg. 20): This section explains that the [NIH Equity Committee](#) was formed as part of efforts to facilitate information sharing.

- How will this committee work to ensure inclusion of scientists with disabilities?
- The link to the Committee includes information on the [Gender Inequality Task Force](#), formed in response to studies on gender inequality in biomedicine. It would be beneficial to the Strategic Plan if a similar Task Force were established in response to underrepresentation of scientists with disabilities in biomedicine.

Paragraph 2 (pg. 20): The Implicit Bias training is referenced again in the Strategic Plan here; it is mentioned that the e-training is being further developed to provide strategies for “creating psychological safety and enhancing employee engagement.”

- Since the Implicit Bias training is lacking people with disabilities (See Paragraph 6 under Goal 1, above), this is also an area where inclusion of people with disabilities can be expanded upon.

Paragraph 2 (pg. 20): Discusses the communications plan that will cover DEIA issues through social media, a COSWD blog, scientific reports, and speakers.

- Will the communication plan include targeted efforts directed at researchers with disabilities and organizations representing researchers focused on disability-related research?
- Will these communication plans be accessible so that anyone, including those with a disability, are able to view the various sources with ease?

Disseminating Forward (pg. 20): Discusses responding to stakeholder needs in order to disseminate evidence.

- Who are the stakeholders?
- Does this include stakeholders with disabilities and organizations with disability-related focus?

Through Collaborations (pg. 20): Discusses importance of widely and effectively disseminating evidence via collaboration with internal and external stakeholders and includes reference to the [Scientific Workforce Diversity Seminar Series](#) on important DEIA topics.

- What are the plans for including persons with disabilities and persons with disability-related expertise among the collaborators?
- What strategies and tactics are being taken to expand and improve disability-specific topics and inclusion of disability perspective in the presentation of generic topics?

Objective 2.1 Tactics (pg. 22): Describes tactic of establishing and hosting forums for more expansive discussion and engagement on specific DEIA efforts. Also, describes forums that have attempted to hire cohorts of scientists to enhance diverse perspectives.

- What strategies and tactics are being planned to include disability-specific efforts (e.g., accessibility of websites, online systems, and mobile apps) and include disability-specific implications of generic topics?

- What data has been collected regarding the success in hiring cohorts of scientists with disabilities to enhance diverse perspectives?

GOAL 3: ACT ON THE EVIDENCE

The third goal articulated in the Strategic Plan focuses on acting on the evidence by advancing integrated, institution-wide systems to address bias, equity, mentoring, and work-life issues and describes efforts by COSWD and others to recruit and provide professional development for exceptional scientists, at various stages, with a strong commitment to diversity (page 5 and pages 23-25).

[The COSWD Recruitment Search Protocol \(pg. 23\)](#): Identifies highly qualified, diverse candidates for various scientific positions.

- What strategies and tactics are being planned to identify and ensure the participation of candidates with disabilities?

[Faculty Institutional Recruitment for Sustainable Transformation \(FIRST\) \(pg. 23\)](#): Shows that cluster hiring leads to more diverse, inclusive research environments, with built-in networks increasing retention, improving socialization, and reducing isolation among diverse faculty. In 2021, funding was awarded to six institutions.

- What requirements are included in agreements (contracts, grants, or cooperative agreements) to ensure participation by faculty with disabilities, including criteria in future RFPs?
- Are institutions required to disaggregate data to determine outcomes for faculty with disabilities?

[Distinguished Scholars Program \(pg. 23\)](#): Uses a cohort recruitment model to select faculty who have demonstrated a commitment to diversity and inclusion.

- What requirements are included in agreements (contracts, grants, or cooperative agreements) to ensure participation by faculty with disabilities?
- Are institutions required to disaggregate data to determine outcomes for faculty with disabilities?

[Future Research Leaders Conference \(pg. 24\)](#): Focuses on attracting and providing career guidance to early-career scientists interested in pursuing careers in NIH's Intramural Research program.

- What efforts have been made to identify and ensure the participation of candidates with disabilities?

[Diversity Program Consortium \(pg.24\)](#): Focusing on developing, implementing, assessing, and disseminating innovative, effective approaches to research, training, and mentoring.

- What efforts are being made to ensure that research, training, and mentoring approaches are disability-inclusive?

Acting Forward (pgs. 24-25): 6 different programs were used as examples of “ongoing NIH DEIA-related funding programs” to address a range of talent life cycle stages.

- Only two of these programs, [*Research Supplements to Promote Diversity in Health-Related Research \(PA-21-071\)*](#) and [*Maximizing Opportunities for Scientific and Academic Independent Careers \(MOSAIC\)*](#), actually encourage applications to support researchers with disabilities. How many of these administrative supplements and awards went to people with disabilities? NIH should publicly share annual utilization and expenditure data, disaggregated by Institute, Center, and grantee institution, to help advocates better understand if these efforts are reaching this underrepresented group as intended.
- The NIH encourages applicants with disabilities to apply for [*Science Education Partnership Award \(SEPA\)*](#), supports researchers from diverse backgrounds, and suggests education programs for children and adolescents with disabilities. How do these programs address accessibility and inclusion?
- The [*Artificial Intelligence/Machine Learning Consortium to Advance Health Equity and Research Diversity \(AIM-AHEAD\)*](#) does not recognize people with disabilities as an underrepresented and underserved community, but researchers with disabilities clearly have “potential to contribute new expertise, data, recruitment strategies, and cutting-edge science,” and to inform the field on the most urgent research questions.
- The National Institute on Minority Health and Health Disparities’ (NIMHD) [*Research Centers in Minority Institutions \(RCMI\)*](#) program supports specialized research centers in institutions that offer doctoral degrees in the health professions or the sciences related to health. Are any of these Centers focused on disability or rehabilitation research, particularly given the high rates of disability within many minority communities?
- The [*Transformative Research to Address Health Disparities and Advance Health Equity Initiative*](#) requires grantees to develop a proposal that “includes a ground-breaking intervention component and focuses on one or more NIH-designated populations that experience health disparities in the U.S.” As the DRRC has noted in the past, people with disabilities are not currently designated as a health disparity population by NIH. One of the recent program grantees is Gallaudet University, so disability research can be funded through this mechanism, but it should be more actively encouraged.

Through Collaborations (pg. 25):

- Similar to the Collaborations sections under Goals 1 and 2, what strategies and tactics will be adopted to ensure that collaborations toward DEIA program development include people with disabilities?

Through Accountability (pg. 25):

- Similar to the Accountability sections under Goals 1 and 2, what strategies and tactics will be adopted to ensure the inclusion of people with disabilities, including search committees?

- How is progress toward DEIA tracked in the scientific workforce in order to determine progress from a disability perspective?

CONCLUSION

The COSWD Strategic Plan (2022-2026) “Great Minds Think Differently” provides an extraordinary opportunity to facilitate and advance diversity, equity, inclusion, and accessibility for underrepresented groups in the scientific workforce. It is our expectation, that the goals and objectives of the Strategic Plan to BUILD, DISSEMINATE, and ACT on evidence to effect change in the scientific workforce will be inclusive of scientists and researchers with disabilities at the initial design stages (not as after-thoughts) and will achieve positive and sustainable outcomes for scientists and researchers with disabilities, consistent with Executive Order 13985 and Executive Order 14035.

We appreciate your consideration of these recommendations and NIH’s ongoing efforts to advance diversity, equity, inclusion, and accessibility across NIH’s Institutes and Centers. We look forward to continuing to engage with NIH on these issues, and hope that these recommendations will help to guide an equitable response to COSWD’s charge that includes people with disabilities. We will follow up directly with your office regarding scheduling a meeting to discuss these items. If you have any questions, please contact the DRRC coordinators, Peter Thomas and Joe Nahra, at Peter.Thomas@PowersLaw.com and Joseph.Nahra@PowersLaw.com, or call 202-466-6550.

Sincerely,

The Undersigned Members of the Disability and Rehabilitation Research Coalition Steering Committee

American Academy of Physical Medicine and Rehabilitation
American Congress of Rehabilitation Medicine
American Occupational Therapy Association
American Physical Therapy Association
Association of Academic Physiatrists
Brain Injury Association of America
National Association of Rehabilitation Research and Training Centers

CC:

Dr. Lawrence Tabak, Acting Director, National Institutes of Health

Dr. Steve Barnett, Co-Chair, ACD WGD Subgroup on People with Disabilities

Dr. Lisa Iezzoni, Co-Chair, ACD WGD Subgroup on People with Disabilities

Dr. Bonnielin Swenor, Co-Chair, ACD WGD Subgroup on People with Disabilities

Dr. Kathleen Mann Koepke, Chair, NIH ABILITIES Employee Resource Group

Adam Politis, Acting Principal Strategist for People with Disabilities, NIH Office of Equity, Diversity, and Inclusion

David Rice, Acting Director, Special Emphasis Program Branch, Diversity and Inclusion Division, NIH Office of Equity, Diversity, and Inclusion

Dr. Alison Cernich, Deputy Director, National Institute on Child Health and Human Development

Dr. Theresa Cruz, Director, National Center for Medical Rehabilitation Research

Dr. Anjali Forber-Pratt, Director, National Institute on Disability, Independent Living, and Rehabilitation Research

Dr. Alondra Nelson, Director, White House Office of Science and Technology Policy

Dr. Francis Collins, Acting Science Advisor to the President

Andres Gallegos, Chairman, National Council on Disability

Day Al-Mohamed, Director of Disability Policy, Domestic Policy Council