

February 10, 2022

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

Via Electronic Mail to <a href="mailto:COSWDStrategicPlan@nih.gov">COSWDStrategicPlan@nih.gov</a>

Re: Disability and Rehabilitation Research Coalition Comments on Draft NIH Chief Officer for Scientific Workforce Diversity Strategic Plan for Fiscal Years 2022-2026: "Great Minds Think Differently"

Dear Dr. Bernard:

On behalf of the Disability and Rehabilitation Research Coalition (DRRC) Steering Committee, we appreciate the opportunity to comment on the National Institutes of Health's (NIH) Request for Information on the Draft NIH Chief Officer for Scientific Workforce Diversity (COSWD) Strategic Plan for Fiscal Years 2022-2026 (NOT-OD-22-054). We applaud NIH for its ongoing focus on diversity, equity, inclusion, and accessibility and look forward to continuing to work with you and your colleagues at NIH to break down systemic barriers and achieve the outcomes enunciated in President Biden's Executive Orders 13985 and 14035.

The DRRC is a coalition of 25 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, independent living, 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, ethnicity, 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. 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.

### **OVERARCHING COMMENTS**

DRRC offers the following overarching comments regarding the Message from the Chief Office and the draft Strategic Plan.

- 1) Historically, COSWD was established to address the disparities in funding of NIH research awards to racial and ethnic minorities. Given the issuance of Executive Order (EO) 14035 "Diversity, Equity, Inclusion, and Accessibility in the Federal Workforce," it is essential that the Message from the Chief Office and Introductory section of the Strategic Plan be modified to:
  - Recognize the breadth of the populations covered, including individuals with disabilities (rather than waiting until page 10 of the document to recognize individuals with disabilities and other protected classes).
  - Recognize that the Strategic Plan is not limited to "diversity" (which is referred to on numerous occasions) but rather addresses "diversity, equity, inclusion, and accessibility" (DEIA), which is the focus of EO 14035, but is referred to on an inconsistent basis in the Strategic Plan.
  - Include definitions for the key terms "diversity," "equity," "inclusion," and "accessibility"—using the definitions of these terms set out in the EO 14035.
- 2) Recognizing that COSWD's <u>current</u> strategic plan does not focus on individuals with disabilities and COSWD staff does not include individuals with disabilities nor individuals with experience and expertise in disability policy, the final Strategic Plan should include specific initiatives targeted at expanding and improving diversity, equity, inclusion, and accessibility for individuals with disabilities, including intramural research programs, extramural research programs, and the external biomedical scientific workforce. Also, the Strategic Plan should include strategies addressing the need for COSWD to diversify its own staff to include individuals with disabilities and disability expertise.
- 3) The draft Strategic Plan (page 16) refers to the Subgroup on Individuals with Disabilities (cochaired by Drs. Iezzoni, Swenor, and Bernard). This Subgroup is charged with supporting the Advisory Committee to the NIH Director (ACD) Working Group on Diversity (WGD) to assist in advising the NIH Director on how to best support individuals with disabilities in the scientific workforce. The subgroup will systematically identify:
  - Strategies to enhance data collection focused on individuals with disabilities in the scientific workforce.
  - Current data and trends on the prevalence of individuals with disabilities in the scientific workforce at various career stages.
  - Evidence-based practices for supporting individuals with disabilities, accounting for variation in disability type.
  - Programs with demonstrated success in supporting individuals with disabilities.
  - Perspectives of individuals with disabilities.

The disability and rehabilitation research community is deeply invested in the work of this Subgroup, and hopes that they will encourage the ACD to systematically review disability inclusion efforts within the NIH-wide programs listed on pages 21 and 22, and within NIH

DEIA-related programs like the Maximizing Opportunities for Scientific and Academic Independent Careers (MOSAIC) program and diversity supplements. Are researchers with disabilities included in these efforts? COSWD should ensure that input and recommendations by the Subgroup are reflected in the final Strategic Plan.

- 4) Under "References" (pages 26-28) there are 30 footnotes, of which one-third specifically refer to race, ethnicity, or gender. None of the footnotes include a reference to disability. Before the Strategic Plan is finalized, COSWD should expand the citations to include research that focuses on or at least includes a representative sample of individuals with disabilities.
- 5) Given the additional focus in EO 14035 on "accessibility" as part of DEIA to ensure that opportunities provided to individuals with disabilities are as effective and meaningful as those provided to others, it is incumbent on COSWD to include in the Strategic Plan specific initiatives and language focused on accessibility and usability of communication, including accessibility and usability of platforms, notifications, conferences, etc.
- 6) Consider modifying the sequence of the "strategies." Currently, the order is "collaboration," "accountability," and then "evaluation." Page 13 the draft correctly states that "evaluation" is the core of the COSWD's pursuit of evidence-based goals, informing program management and ensuring accountability." Also, page 14 states "process evaluations will allow us to ascertain whether programs were implemented as intended." DRRC agrees with these statements and thus recommends the order of the strategies be revised throughout the document as follows: "collaboration," "evaluation," and "accountability."

#### **SPECIFIC SUGGESTIONS**

Set out below are specific suggestions organized by page number in the draft Strategic Plan.

## **Title Page**

 To reflect the scope of EO 14035, consider modifying the official name of the office from "NIH Chief Officer for Scientific Workforce Diversity" to "NIH Chief Officer for Scientific Workforce Diversity, Inclusion, Equity, and Accessibility" and retain the acronym "COSWD."

#### Page 1

1. Make technical and conforming changes consistent with suggestions below.

### Page 2

1. Update the Message to reflect the issuance of EO 14035 and the broad scope of DEIA initiatives as including, among others, racial and ethnic groups, individuals with disabilities, women, and disadvantaged groups (see page 10 of the draft).

No changes suggested.

## Page 4

- 1. Under "Purpose" paragraph, line 5, delete "diversity" and insert "diversity, equity, inclusion, and accessibility".
- 2. Under "Goals and Strategies" paragraph, line 4, delete "diversity" and insert "diversity, equity, inclusion, and accessibility".
- 3. In the box, after "Scope" add text to explain the scope of the Strategic Plan includes "Diversity, Equity, Inclusion, and Accessibility" and define the terms using the definitions in EO 14035.
- 4. In the box, after defining DEIA, explain that the Strategic Plan covers, among others, racial and ethnic groups, individuals with disabilities, women, and disadvantaged groups (see page 10 of the draft).

# Page 5

- 1. Under "Goal 1: BUILD the evidence" paragraph, line 2, delete "diversity" and insert "diversity, equity, inclusion, and accessibility".
- 2. Under "Objective 1.1, line 2, delete "diversity" and insert "diversity equity, inclusion, and accessibility".
- 3. Under "Objective 1.2" insert before the period ", especially the NIH Office of Equity, Diversity, and Inclusion".

### Page 6

- 1. Under "MISSION" delete "diversity, using evidence-based approaches to catalyze cultures of inclusive excellence" and insert "diversity, equity, inclusion, and accessibility, using evidence-based approaches to catalyze cultures of excellence".
- 2. After "VISION and "MISSION" insert "DEFINITIONS" and include definitions for the terms "diversity," "equity," "inclusion," and "accessibility" using the definitions included in EO 14035.
- 3. After "Definitions" add "SCOPE" and include content explaining that the Strategic Plan covers racial and ethnic groups, individuals with disabilities, women, and disadvantaged groups (See page 10of the draft)
- 4. Under "Goal 1" delete "diversity" and insert "diversity, equity, inclusion, and accessibility".
- 5. Under "Cross-Cutting Strategies to Pursue Goals," switch order of strategies to: "Collaborations, Evaluation, and Accountability".

#### Page 7

No changes suggested.

No changes suggested.

#### Page 9

No changes suggested.

### Page 10

No changes suggested.

## Page 11

1. Under "Effective Programs" delete "and interventions to enhance diversity and develop cultures of inclusive excellence" and insert "and interventions to enhance excellence through diversity, equity, inclusion, and accessibility".

# Page 12

1. Under "Collaborations" at paragraph 2, insert in the appropriate place "Office of the Chief Information Officer" and "Affinity Groups (Employee Resource Groups)".

# Page 13

- 1. Switch order, inserting "Evaluation" before "Accountability".
- 2. Under "Value of Evaluations for COSWD's Goals" insert the following bullets:
  - "Allow leadership to ascertain whether initiatives are successful."
  - "Develop metrics for holding individuals accountable for performance."

## Page 14

- 1. Switch order of columns under 'Strategies" as follows: "Collaborations, Evaluation, and Accountability".
- 2. Under Collaborations "Build the Evidence" delete "diversity, equity and inclusion" and insert "diversity, equity, inclusion, and accessibility".
- 3. Under Evaluations "Disseminate the Evidence" delete "Assess the effectiveness of communication strategies" and insert "Assess the effectiveness, accessibility, and usability of communication strategies".

## Page 15

- 1. Under "Goal 1: Build the Evidence", in the box delete "diversity" and insert "diversity, equity, inclusion, and accessibility."
- 2. Under "Progress and Plans to Build the Evidence" in line 3 delete "diversity" and insert "diversity, equity, inclusion, and accessibility".

- 3. Under "Progress and Plans to Build the Evidence" please ascertain whether the focus on "implicit bias" and programs intended to "reduce biases" address these issues from a disability perspective and, if not, modify the Strategic Plan to include a disability perspective in the future.
- 4. Under "Developing and Testing New Insights" paragraph 1 at line 2 delete "diversity" and insert "diversity, equity, inclusion, and accessibility".
- 5. Under "Developing and Testing New Insights" paragraph 1, at the appropriate place insert "Employee Resource Groups".
- 6. Under "Developing and Testing New Insights" in paragraph 2, the last sentence please ascertain whether the review of the scientific literature includes a review of the literature of implicit biases from a disability perspective.

- 1. The first full paragraph refers to the Subgroup on Individuals with Disabilities (co-chaired by Dr. Bernard). The Subgroup on Individuals with Disabilities is charged with supporting the ACD WGD to assist, in turn, the ACD with its advice to the NIH Director on how to best support individuals with disabilities in the scientific workforce. We suggest describing the target population clearly, avoiding the euphemism "differently abled individuals" (See, for example, <a href="https://www.betterup.com/blog/differently-abled">https://www.betterup.com/blog/differently-abled</a>). What steps are being taken to ensure that input and recommendations by the Subgroup will be reflected in the final Strategic Plan?
- 2. The last sentence in the first paragraph states "Through collaboration with the subgroup, the COSWD will enhance its focus on accessibility in the scientific workforce." What efforts are being made to collaborate with accessibility experts at the NIH Office of Diversity, Equity, and Inclusion (EDI) and disability-focused Employee Resource Groups? What specific efforts will be included in the final version of the Strategic Plan to address 'diversity, equity, and inclusion" and more specifically accessibility?
- 3. Under "Building Forward" paragraph 1, line 2 delete "diversity" and insert "diversity, equity, inclusion, and accessibility".
- 4. Change the order of strategies as follows: "Through Collaboration" "Through Evaluation" and "Through Accountability".

## Page 17

- 1. Under "Strategies to Build the Evidence" switch the order of the columns to read "Collaborations, Evaluation, and Accountability".
- 2. In the box under "Collaborations" delete "diversity, equity, and inclusion" and insert "diversity, equity, inclusion, and accessibility".
- 3. In the box under "Evaluation" delete "diversity initiatives" and insert "diversity, equity, inclusion, and accessibility initiatives".
- 4. Under "Objectives and Tactics to Build the Evidence" under "Objective 1.1" heading delete "diversity" and insert "diversity, equity, inclusion, and accessibility".
- 5. Under Objective 1.1 "Tactics" in third bullet, line 3, delete "diversity issues" and insert "diversity, equity, inclusion, and accessibility issues".

- 6. Under "Objective 1.2" "Tactics" in bullet 1, delete "diversity strategies" and insert "diversity, equity, inclusion, and accessibility strategies"; and after "NIH UNITE initiative" insert ", "Office of Equity, Diversity, and Inclusion".
- 7. Under "Objective 1.2, "Tactics" bullet 2 and bullet 3 delete "diversity" and insert "diversity, equity, inclusion, and accessibility".

- 1. Under "Progress and Plans to Disseminate the Evidence" paragraph 1, lines 2 and 4 and paragraph 3, lines 2 and 4 delete "diversity" and insert "diversity, equity, inclusion, and accessibility".
- 2. Under "Progress and Plans to Disseminate the Evidence" paragraph 3, line 4 delete "platforms" and insert "accessible and usable platforms".
- 3. Under "Disseminating Forward" line 5 delete "diversity efforts" and insert "diversity, equity, inclusion, and accessibility efforts".
- 4. Under "Disseminating Forward" line 6 delete "platforms" and insert "accessible and usable platforms".

# Page 19

1. Switch the order of the topics to read "Through Evaluation" and "Through Accountability".

### Page 20

- 1. Under "Strategies to Disseminate the Evidence" switch the order of the columns to read "Collaborations, Evaluation, Accountability".
- 2. Under Objective 2.1, "Tactics" bullet 1, delete "diversity issues" and insert "diversity, equity, inclusion, and accountability issues".
- 3. Under Objective 2.1, "Tactics" bullet 3, delete "social media platforms" and insert "accessible and usable social media platforms".
- 4. Under Objective 2.2 "Tactics" bullet 2, delete "speaking engagements" and insert "speaking engagements made accessible both physically and virtually".

## Page 21

- 1. Under Objective 2.3 "Tactics" delete "e.g., social" and insert "e.g., accessible and usable social media".
- 2. Under "Goal 3: Act on the Evidence" in the box delete "bias, equity" and insert "bias, diversity, equity, inclusion, and accessibility".
- 3. Under "Progress and Plans to Act on the Evidence" "Recruiting and Developing Talent" line 3, delete "diversity" and insert "diversity, equity, inclusion, and accessibility".

#### Page 22

No changes suggested.

- 1. The draft includes numerous examples of ongoing NIH DEIA-related funding programs. Before the Strategic Plan is finalized, COSWD should undertake a comprehensive review of these programs to 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).
- 2. We note that one of the key programs listed in this document, *Transformative Research to Address Health Disparities and Advance Health Equity*, funds projects that include "a ground-breaking intervention component" and focus on "one or more NIH-designated populations that experience health disparities in the U.S." People with disabilities are not currently designated as a health disparity population by the National Institute on Minority Health and Health Disparities. Based on the current research into disability disparities, DRRC strongly supports making such a designation. The National Council on Disability and other advocacy groups are demanding executive action on this matter (See <a href="https://ncd.gov/publications/2021/ncd-letter-nimhd-ahrq-health-disparity-population-designation">https://ncd.gov/publications/2021/ncd-letter-nimhd-ahrq-health-disparity-population-designation</a>).

## Page 24

1. Switch the order of presentation to read "Through Collaborations, Through Evaluations, Through Accountability".

#### Page 25

- 1. Under "Objectives and Tactics to Act on the Evidence" Objective 3.1 "Tactics" bullet 1, delete "diversity" and insert "diversity, equity, inclusion, and accessibility".
- 2. Under Objective 3.2 heading delete "diversity metrics" and insert "diversity, equity, inclusion, and accessibility metrics".

#### Pages 26-28

Under "references" there are 30 footnotes, of which one-third specifically refer to race, ethnicity, or gender. None of the footnotes include a reference to disability. Of the remaining two-thirds, how many of the references include disability status? COSWD should expand the research base to include studies that focus on or at least include a representative sample of individuals with disabilities.

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We thank you for the opportunity to comment on the next COSWD strategic plan and on NIH's ongoing efforts to advance equity, diversity, inclusion, and accessibility 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 COSWD's charge. If you have any questions, please contact the DRRC coordinators at <a href="Peter.Thomas@PowersLaw.com">Peter.Thomas@PowersLaw.com</a>, or call 202-466-6550.

Sincerely,

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

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

## CC:

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

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

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