ACD WGD Subgroup on Individuals with Disabilities Report

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December 9, 2022

Background

Origin

- Launched in August 2021

- Chaired by Drs. Bonnielin Swenor, Lisa Iezzoni, and Steven Barnett

- Charge:
  - Support the ACD WGD to assist, in turn, the ACD with its advice to the NIH Director on how to best support the inclusion of people with disabilities (PWD) in the scientific workforce
  - Codify detailed, proposed suggestions in a written report

- https://acd.od.nih.gov/working-groups/disabilitiessubgroup.html

Members

- **Kim D. Anderson, Ph.D.**, Case Western Reserve University
- **Steven Barnett, M.D.**, University of Rochester School of Medicine & Dentistry (Co-Chair)
- **Theresa Cruz, Ph.D.**, National Institutes of Health
- **Alberto Esquenazi, M.D.**, Albert Einstein Medical Center
- **Jean P. Hall, Ph.D.**, University of Kansas
- **Susan M. Havercamp, Ph.D.**, The Ohio State University Nisonger Center
- **Lisa I. Iezzoni, M.D., M.Sc.**, Harvard Medical School (Co-Chair)
- **Kathleen Mann Koepke, Ph.D.**, National Institutes of Health
- **Corey L. Moore, Rh.D.**, Langston University
- **Adam Politis, M.S.**, National Institutes of Health
- **Bonnielin Swenor Ph.D., M.P.H.**, Johns Hopkins University (Co-Chair)
- **Philip Zazove, M.D.**, University of Michigan Medical School
- **David P. Rice, Jr.**, National Institutes of Health

Scope

- Strategies to enhance data collection focused on PWD in the scientific workforce

- Data on the prevalence of PWD in the scientific workforce at various career stages

- Evidence-based practices for supporting the inclusion of PWD, accounting for variation in disability type

- Programs with demonstrated success in supporting the inclusion of PWD

- Perspectives of PWD

The initial scope of the group's work broadened to suggest policy changes to expand research focused on addressing the health and health care disparities affecting PWD and increasing the inclusion of PWD in research studies.

- **Medical Model vs. Social Model of Disability[7,8]**

  - *Medical Model* – Views disability as a disease or impairment that can be "corrected" through treatment

  - *Social Model* – Focuses on how ableist and discriminatory attitudes, physical environments, and other barriers inhibit PWD from fully participating in society

- **The World Health Organization's definition** views "disability" as an "umbrella term," that accounts for the interactions between contextual factors, including environmental (e.g., social and structural barriers) and personal factors (e.g., age, gender, social background), and health conditions (e.g., diseases, disorders, and injuries)[8,9]

Ableism and Language

- **Ableism –** The belief that PWD are flawed and less valuable than nondisabled people[12]

  - "People with disabilities are intellectually inferior"

  - "Of course they want our pity and help!"

- Historically, language used to indicate disability **conveyed bias or discriminatory attitudes**; such language can increase stigma and exclusion of PWD[13]

  - E.g., "special needs," "differently-abled," "handicapped," and "mentally or physically challenged"

Executive and Legislative Mandates

- **Rehabilitation Act, Section 504 (1973)** – Prohibits discrimination on the basis of disability by federal executive agencies and organizations that receive federal funding, including NIH-supported scientific research and training programs at postsecondary institutions

- **Americans with Disabilities Act (1990)** – Mandates equal opportunity for disabled people to participate and benefit from public and private programs and services

- **Affordable Care Act, Section 4302 (2010)** – Requires the Secretary of HHS to establish data collection standards for many demographic aspects, including disability status

- **Executive Order 14035 DEIA in the Federal Workforce (2021)** – Directs the government to become a model employer for individuals with disabilities

- **Executive Order 13985 Advancing Equity for Underserved Communities (2021)** – Directs the government to pursue a comprehensive, data-focused approach to advancing equity for underserved groups, including PWD
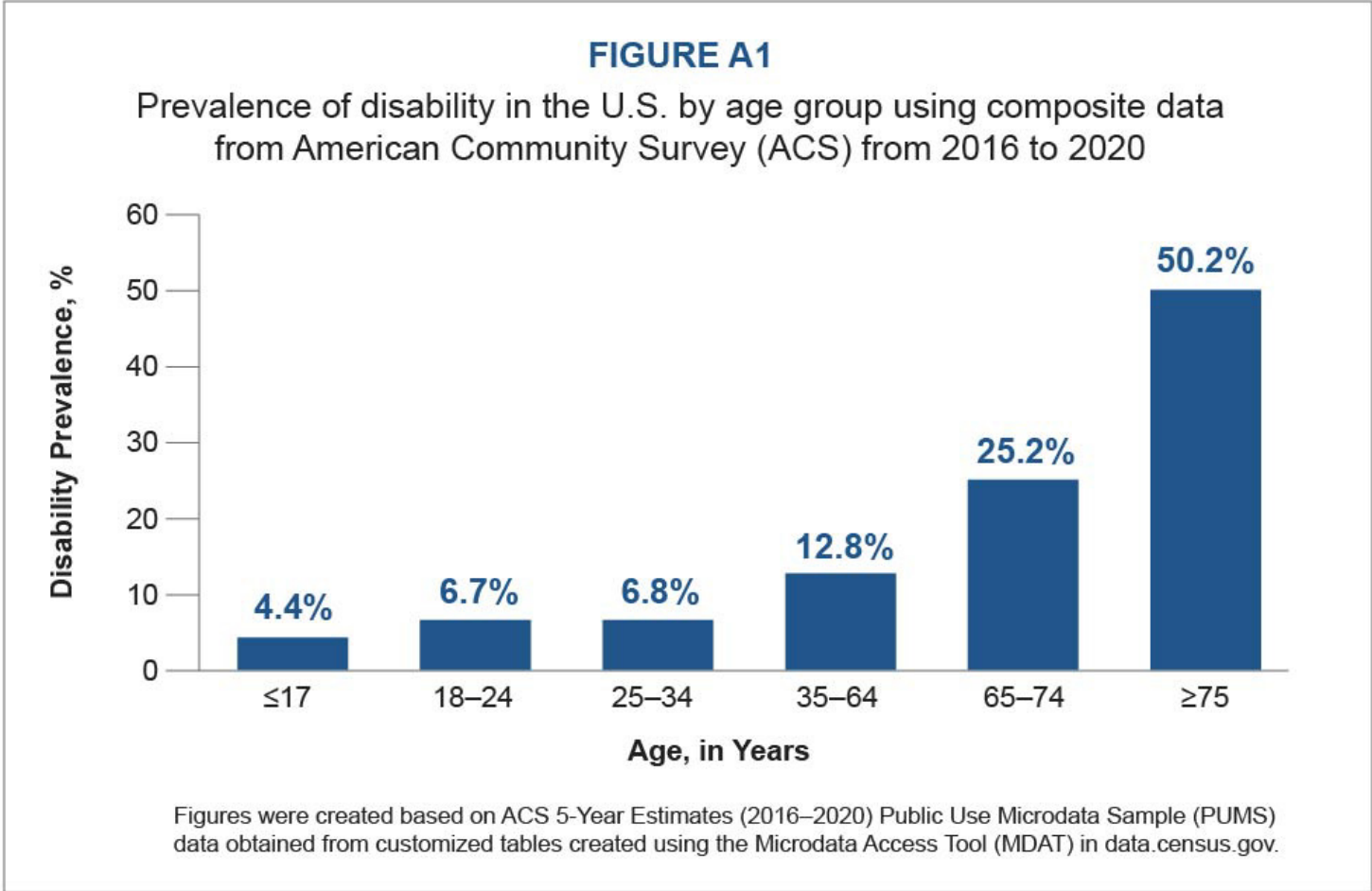
Disability Data

People with disabilities comprise the largest minority population in the United States

- PWD represent over 27% of the United States adult population (over 67 million adults)[48]

- PWD - single largest minority population and fastest growing minority population[48]

- Disabilities are diverse

  - Can be congenital, arise suddenly, or progress over time

  - Some apparent to others; others are invisible

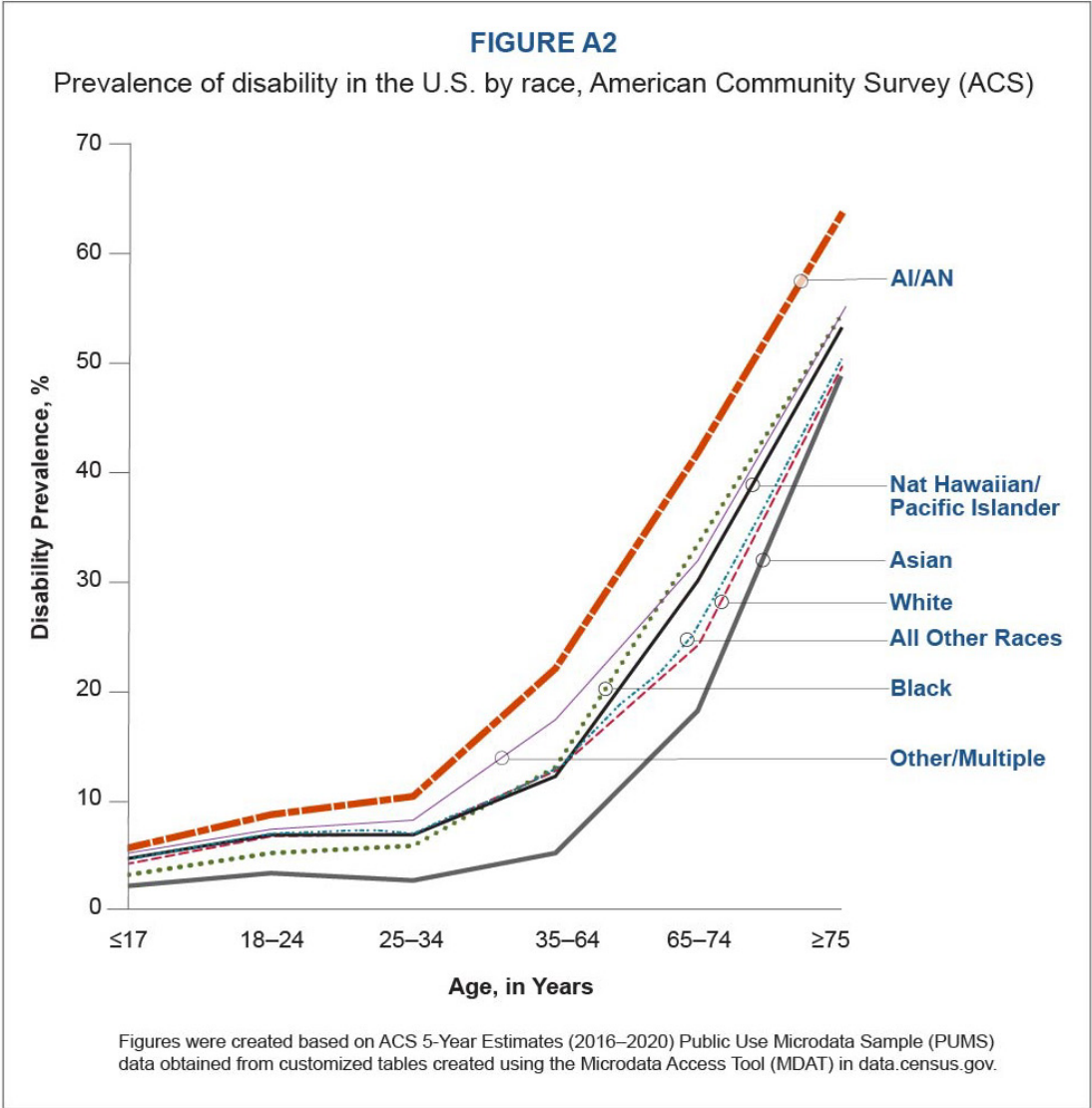 - Some people have multiple disabilities

Disability prevalence increases with age

- Disabilities - relatively common (12.8%) during active years of research careers (ages 35 to 64)

- Approximately 7% of adults during undergraduate and graduate training years (ages 18 to 24) and 7% of adults during postdoctoral training years (ages 25 to 34) have a disability

FIGURE A1

Prevalence of disability in the U.S. by age group using composite data from American Community Survey (ACS) from 2016 to 2020

Figures were created based on ACS 5-Year Estimates (2016–2020) Public Use Microdata Sample (PUMS) data obtained from customized tables created using the Microdata Access Tool (MDAT) in data.census.gov.

Disability prevalence varies by racial groups

- Across all ages, disability prevalence is highest among American Indians and Alaskan Natives (AI/AN)

- Disability prevalence is lowest among Asians

FIGURE A2

Prevalence of disability in the U.S. by race, American Community Survey (ACS)

Figures were created based on ACS 5-Year Estimates (2016–2020) Public Use Microdata Sample (PUMS) data obtained from customized tables created using the Microdata Access Tool (MDAT) in data.census.gov.

Intersectionality

- There is a lack of intersectional data on researchers with disabilities

- Disabled researchers with intersectional marginalized identities face more barriers and are less represented

  - AI/AN served as principal investigators (PIs) on 114 NIH research grants in 2021, compared to 28,780 White PIs[58]

  - Specific intersectional identities put people at higher risk for disability-related harassment, including being female, older, a racial minority, and having a behavioral disability[34]

  - PWD at Minority-Serving Institutions (MSIs) experience additional barriers in the areas of research skill building and infrastructure[31,32]

Disabled people are underrepresented in the NIH Workforce

- In FY 2021 Q2, only 7.7% of the NIH Workforce disclosed a disability
  - 2.1% of employees reported a targeted disability; 5.6% reported a non-targeted disability
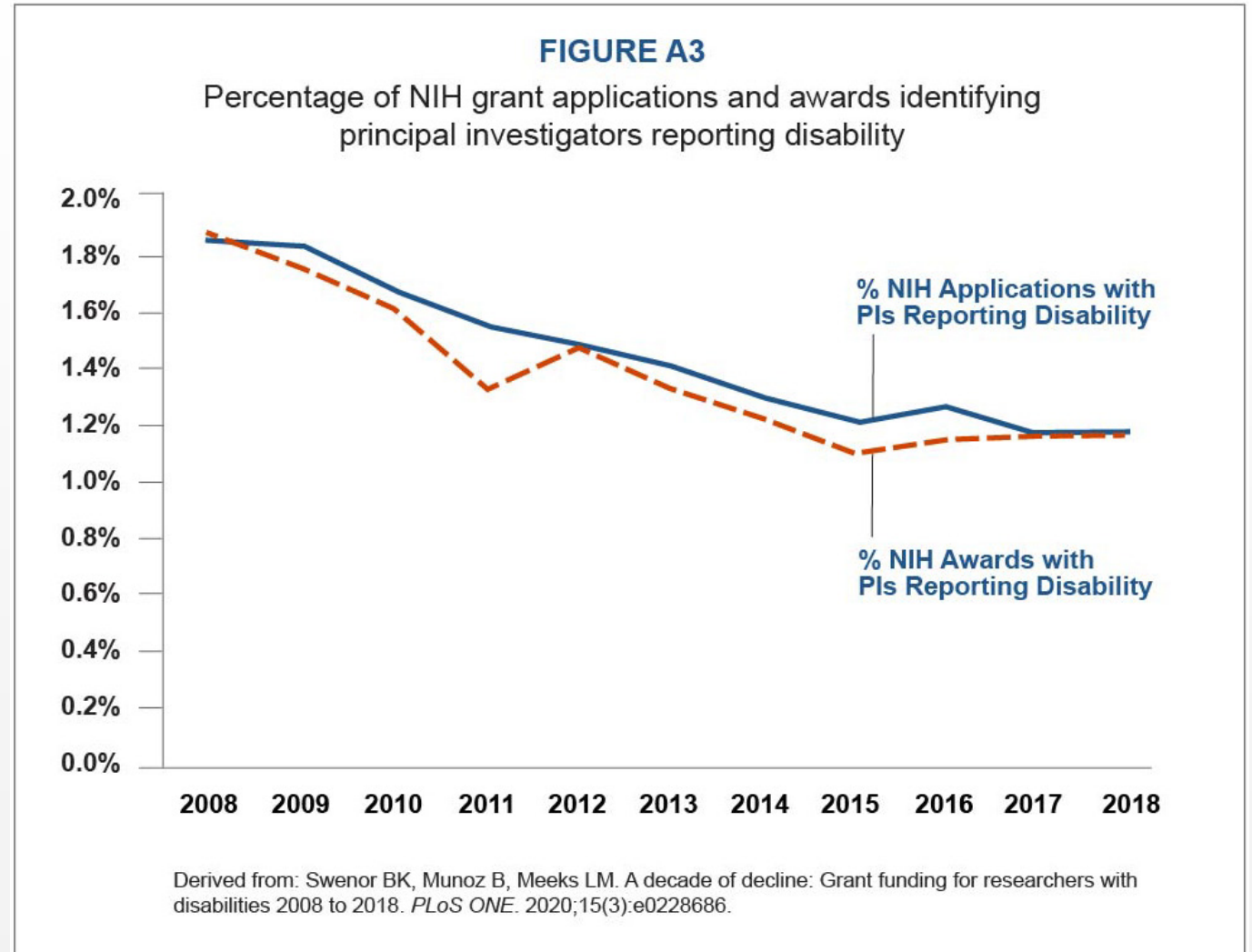 - 6.5% of employees chose not to report disability status

NO DISABILITY
85.8% (15,845)

NOT IDENTIFIED
6.5% (1,210)

NON-TARGETED DISABILITY*
5.6% (1,028)

TARGETED DISABILITY*
2.1% (395)
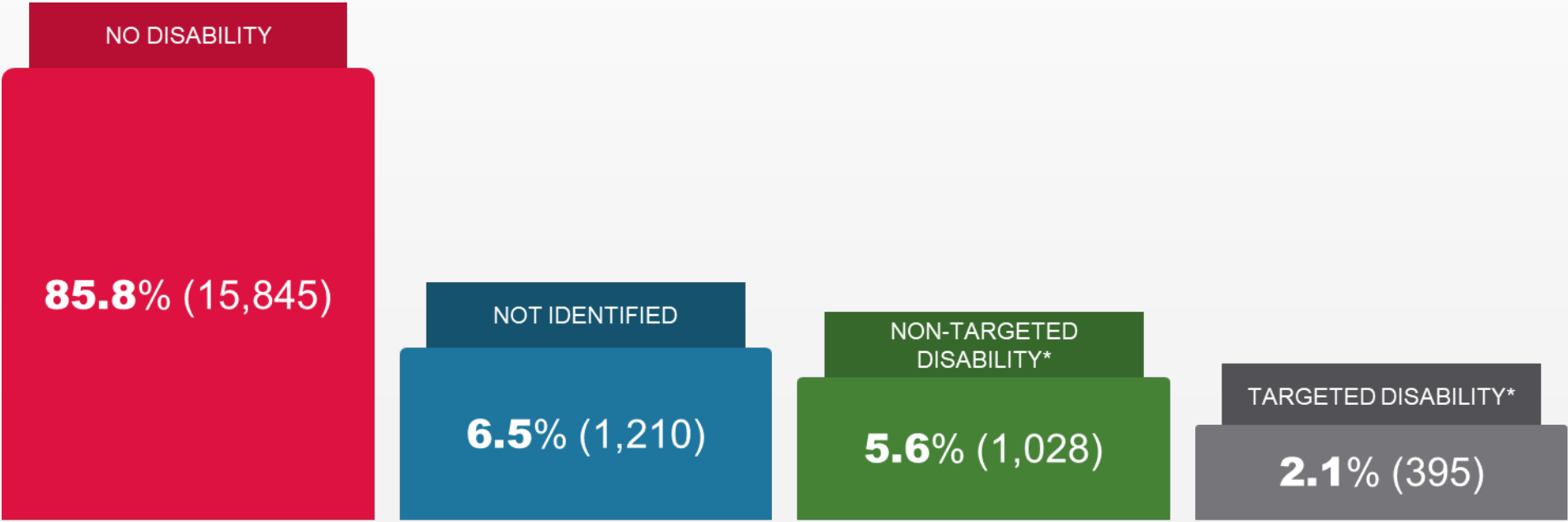
*Total Reportable Disability = Non-Targeted Disability + Targeted Disability

Disabled people are underrepresented in the scientific workforce

- PWD represent approximately **9% of the scientific workforce**[2-4]

- Data from the Women, Minorities, and Persons with Disabilities in Science and Engineering 2021 report indicate that disability representation in the scientific workforce decreases throughout the career path[51]

  - **19%** of undergraduate students
  - **9%** of doctoral students
  - **8%** of postdoctoral students
  - **8%** of assistant professors
  - **10%** of associate and full professors
  - **8%** of department directors, chairs, and chancellors
  - **8%** of university presidents and provosts

- Just under **5% of medical students** and approximately **3% of practicing physicians** report disability[52,53]

Researchers with disabilities are underrepresented in NIH funding

- 2008–2018 decline from 1.9% to 1.2%[49]

- 27.2% of PIs reporting disability supported by NIH funding, compared to 29.7% of those not reporting disabilities[49]

- Diversity Supplements applications FY 2018: 34 of > 1,100 (3%) support disabled researchers[55]

FIGURE A3

Percentage of NIH grant applications and awards identifying principal investigators reporting disability

% NIH Applications with PIs Reporting Disability

% NIH Awards with PIs Reporting Disability

Derived from: Swenor BK, Munoz B, Meeks LM. A decade of decline: Grant funding for researchers with disabilities 2008 to 2018. *PLoS ONE*. 2020;15(3):e0228686.

NIH Disability Data Gaps

- **Few data are publicly available about disability prevalence in NIH and in the broader research workforce or the participation of PWD in NIH-funded studies**
  - Data collection methods should be:
    - Consistent with those used in other HHS agencies
    - Selected in partnership with the disability community
    - Able to support comparisons over time and across workforce diversity efforts

- **NIH's efforts to collect disability data on the research workforce are inadequate**
  - In eRACommons, researchers can only self-report four disability types: mobility/orthopedic, hearing, visual, or other
  - NIH should collect more granular data about disability representation (e.g., types of disabilities, disabled staff and trainees' roles, salaries, and career level)

Suggestions

1. Update the NIH mission statement

2. Establish an NIH Office of Disability Research

3. Establish an NIH Disability Equity and Access Coordinating Committee

4. Develop an internal, NIH-wide effort to identify and address any structural ableism that may exist and promote disability inclusion by:

   a. Fostering support for the equity, inclusion, and belonging of PWD within NIH culture and structure

   b. Advancing disability inclusion and anti-ableism through training, communication, policies, and accessibility

5. Review policy, culture, and structure to identify opportunities to promote disability inclusion in the NIH-funded research workforce

6. Expand efforts to include disability communities and the perspectives of PWD

7. Conduct research on disability health and health care disparities and equity by:

    a. Formally designating PWD as a health disparity population

    b. Funding / promoting research on health and health care disparities experienced by PWD

    c. Collecting data on disability wherever demographic information is collected within NIH data systems

    d. Supporting inclusion of disabled people as research participants

8. Ensure that disability inclusion / anti-ableism are core components of all NIH DEIA efforts

9. Maintain accountability for disability inclusion efforts

DISCUSSION