

VIEWPOINT

Revising NIH's Mission Statement to Remove Ableist Language

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The National Institutes of Health (NIH)—the \$45 billion, federal medical research agency—is considering changing its mission statement.¹ Its current mission statement is as follows:

“To seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.”

The proposed revised mission statement eliminates language about reducing disability:

“To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health and prevent or reduce illness for all people.”

The December 2022 report of the Advisory Committee to the Director Working Group on Diversity, Subgroup on Individuals with Disabilities¹ recommended this change to NIH's mission statement, noting, “The current mission statement could be interpreted as perpetuating ableist beliefs that disabled people are flawed and need to be ‘fixed’.”² Attitudes about disability have changed dramatically over the last half century, largely

gave FDR, socially privileged and previously considered callow with mediocre accomplishments, the empathy and strength of character to become one of the most consequential US presidents.³

Shortly after FDR's death, World War II veterans returning home with extensive physical and emotional injuries catalyzed the US disability civil rights movement. Despite residual impairments, which persisted after medical treatment, they aimed to resume their lives, start families, and contribute to their communities. They demanded accommodations within workplaces and other community settings to facilitate their full participation in daily life. Over the next 30 years, the understanding of disability changed fundamentally. Since the 19th century, a medical model had prevailed, which viewed disability as an individual deficit demanding medical cure; without restoration to putative normalcy, people should accept and live with their loss.⁵ Under the new social model, disability results when societies erect physical, attitudinal, and other barriers to participation in daily life by people who function differently than some supposed norm. Disability is therefore not an individual problem but one imposed on disabled people by societies; it is thus a human rights issue.⁵

Language relating to disability has also evolved over time.⁶ Section 504 of the Rehabilitation Act of 1973 provided the first civil rights protections to

“We cannot be a strong nation unless we are a healthy nation.”

Franklin Delano Roosevelt

driven by disabled people such as those who led and served in the subgroup. NIH's current mission statement has long historical roots, reflective of when it was developed. However, new thinking about disability should propel NIH going forward.

Several decades into the 20th century, a teachable moment was lost when the White House and national press corps hid from the public the fact that Franklin Delano Roosevelt led the nation out of the Great Depression and into the Great War seated in his wheelchair. FDR himself carefully crafted this ruse.³ After polio left him unable to walk at age 39, he worked doggedly with physical therapists to appear to walk by standing on braced legs, rotating his pelvis, and moving forward with someone supporting him at his side. Indeed, on October 31, 1940, when he dedicated NIH's new campus in Bethesda, Maryland, and said, “We cannot be a strong nation unless we are a healthy nation,” FDR stood, clutching a podium on the steps of the just-built administration building before roughly 3000 attendees.⁴ Most Americans accepted the fiction that their president was only a *little lame*. FDR legitimately believed that the country would not accept a disabled president. Many historians argue that confronting polio

people with disabilities, prohibiting discrimination in programs receiving federal funds. This 1973 law used the outdated term *handicapped* throughout. The 1990 Americans with Disabilities Act, which extended civil rights protections to all public programs and to private services that serve the public, used “person-first language” (ie, persons with disabilities) meant to emphasize someone's humanity before recognizing their disability. In 1992, Rehabilitation Act amendments changed the term *handicapped person* to *individual with a disability*. In recent years, the minority and diversity model of disability asserts that disability is 1 component of identity, similar to race, ethnicity, sexual orientation, and gender identity.⁶ This model encourages “identity-first language” (ie, disabled person) to affirm and demonstrate pride in identifying as disabled. The disability social justice movement recognizes that intersectional, marginalized identities compound oppression.

People with disabilities are diverse. Some disabilities are apparent; others are nonapparent. No consensus exists about language choices or even whether people decide to identify as disabled.⁶ As for other marginalized communities, disabled people should have the right to

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claim their identity and use the language they choose. Sometimes people outside the disability community are uncomfortable and seek euphemisms that they perceive accentuate strengths of individuals with disabilities. The phrase *special needs* is often used within educational settings; other euphemisms include *differently abled*, *handicapable*, and *physically challenged*. Many disabled people find these words patronizing or infantilizing and believe that these terms minimize the realities of social oppression.⁶

Even within disability types, individuals can have different views. For example, some people who are deaf view themselves not as disabled but as members of a linguistic minority while others join the broader disability community to contest societal presumptions of normality.⁶ David Rice, then a management analyst at the National Eye Institute who is deaf, motivated changes to the 2013 NIH mission statement, which was “to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life and reduce the burdens of illness and disability.”⁷ Rice asserted that he did not view being deaf as burdensome and sought removal of the phrase about reducing “burden” from NIH’s mission statement. NIH Director Francis Collins was immediately agreeable to the change.⁷ Rice served on the subgroup that recommended further revising of NIH’s mission statement.²

Updating its mission statement will align NIH’s framing of disability with initiatives of other federal agencies. On September 7,

2023, the Office for Civil Rights, US Department of Health and Human Services issued a proposed rule to update and strengthen civil rights protections in health care and other human services programs for persons with disabilities under section 504 of the 1973 Rehabilitation Act (RIN: O945-AA15).⁸ Importantly, § 84.56(b)(1) of the proposed rule prohibits limiting or denying medical treatment “to a qualified individual with a disability when the denial is based on (i) bias or stereotypes about a patient’s disability; (ii) judgments that an individual will be a burden on others due to their disability, including, but not limited to, caregivers, family, or society; or (iii) a belief that the life of a person with a disability has a lesser value than that of a person without a disability, or that life with a disability is not worth living.”

Language matters. The current NIH mission statement suggests erasure, devaluation of an identity and existence that disabled people value and many view with pride. According to the 2011 *World Report on Disability*, “Disability is part of the human condition. Almost everyone will be temporarily or permanently impaired at some point in life....”⁹ Most disabled people, like others, want to maximize the quality of their lives and, as the proposed mission statement suggests, “optimize their health”—recognizing that the word “health” also has various definitions. Revising NIH’s mission statement is necessary and long overdue. This change will guide the research and medical communities to finally acknowledge modern and community-centered views of disability.

ARTICLE INFORMATION

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Additional Information: In addition to Drs Iezzoni and Swenor, the Advisory Committee to the Director Working Group on Diversity, Subgroup on Individuals with Disabilities was cochaired with Steven Barnett, MD, Departments of Family Medicine and Public Health Sciences, University of Rochester School of Medicine and Dentistry; and Rochester Prevention Research Center: National Center for Deaf Health Research, Rochester, New York.

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