

# NIMHD

National Institute on Minority Health  
and Health Disparities

## National Advisory Council on Minority Health and Health Disparities (NACMHD) Working Group on Persons Living with Disabilities

Final Progress Report September 20, 2023

THIS REPORT SUPERCEDES THE PRESENTATION GIVEN TO NACMHD ON  
SEPTEMBER 1, 2023



National Institute  
on Minority Health  
and Health Disparities

## Preface

The National Advisory Council on Minority Health and Health Disparities (NACMHD) Working Group on Persons Living with Disabilities and Health Disparities presents this report to the National Institute on Minority Health and Health Disparities (NIMHD) Director, Dr. Pérez-Stable. It represents the deliberations of a selected subgroup of NACMHD members and external individuals with appropriate expertise who were invited by the NIMHD Director to serve on the committee. As noted in the report, the working group's functional statement was to provide general guidance and strategic direction to NIMHD regarding opportunities to advance science to understand and address health disparities among people living with disabilities. The working group was charged with:

- Reviewing the state of the science on health disparities among persons living with disabilities.
- Providing input on gaps, research needs, and strategic opportunities for health disparities research with an intersectional lens among persons living with disabilities.
- Advising on the benefits and risks of expanding the National Institutes of Health (NIH)-designated health disparity populations to include persons living with disabilities.

Over the past year, the working group convened several content experts on issues experienced by persons living with disabilities, including disability advocates, researchers, and persons with extensive knowledge of the history and mission of NIMHD. This report provides the background on the working group's deliberations and summarizes key presentations that informed our list of considerations.

As noted in the report, it is clear that persons living with disabilities face tremendous health disparities that impact quality of life, morbidity, and mortality, as well as discrimination, based on their abilities and identity. We hope this report will be useful to the NIMHD Director and others charged with considering initiatives to improve the health and well-being of persons living with disabilities.

Sincerely,

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# National Advisory Council on Minority Health and Health Disparities (NACMHD) Working Group to evaluate the risks and benefits of designating persons living with disabilities as a population with health disparities

## Background

In late 2021 and early 2022, NIMHD was asked by the National Council on Disabilities (NCD is an independent federal agency) and the Administration for Community Living to designate persons living with disabilities as a health disparities population and include research on disabilities in the same manner that research on racial and ethnic populations, those of people with lower socioeconomic status, sexual and gender minority groups, and rural populations is classified by NIMHD. In response, NIMHD Director Dr. Eliseo Pérez-Stable decided to obtain advice from the National Advisory Council and others with relevant expertise by convening a working group to evaluate the risks and benefits of designating people living with disabilities as a population with health disparities. The working group was formed officially on September 2, 2022, at the NACMHD meeting. Of note, the NIMHD Director has the final authority to determine which groups are designated as health disparities populations in consultation with the Director of Agency for Healthcare Research and Quality (AHRQ) (Robert O. Valdez, Ph.D.) ([PUBLIC LAW 106-525—NOV. 22, 2000](#)).

## Working group charge

The committee was charged with the following:

- Review the state of the science on health disparities among persons living with disabilities.
- Provide input on gaps, research needs, and strategic opportunities for health disparities research with an intersectional lens among persons living with disabilities.
- Deliberate and advise on the benefits and risks of expanding the NIH-designated health disparity populations to include persons living with disabilities. This will include focusing on the mission, prioritization process, goals, and scientific activities of NIMHD.

## Working group members

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## Meeting schedule and agenda topics

Between September 2, 2022, and August 22, 2023, the working group met virtually and in person (May 2023 NACMHD meeting) approximately 9 times to address its charge. Meetings included presentations from content experts on disparity issues experienced by persons living with disabilities, disability advocates, researchers, and persons with extensive knowledge of the history and mission of NIMHD. Meetings also included extensive committee deliberation to determine considerations for designating persons living with disabilities as a health disparities population based on presentations, literature reviews, current NIH disability funding portfolios review, and other data sources. Appendix B includes the meeting schedule and agenda topics.

### Charge #1. Review the state of the science on health disparities among persons living with disabilities

NIMHD staff conducted a series of brief PubMed literature searches to present the committee with relevant literature on the following topics: Disabilities and prejudice, disabling health, disabilities and patient-provider interactions, disabilities and social identity, disablism health, disabilities and discrimination, disabilities and chronic illnesses, disabilities and health disparities, disabilities and stigma. The search yielded more than 1,300 titles.

#### Definition of health disparities

Health disparities are well documented in the United States and are shaped by the unequal distribution of social, political, and economic resources across demographic subgroups. While disparities in health and health care are often documented for persons from racial and ethnic backgrounds, they occur across many dimensions, including socioeconomic status, sex and gender, and rurality. There are numerous definitions of health disparities, but according to the Centers for Disease Control and Prevention (CDC), health disparities are preventable differences in the burden of disease, injury, violence, or in opportunities to achieve optimal health experienced by racial and ethnic minority groups and other groups or communities that are socially disadvantaged. It was this definition that guided the committee's deliberations and analyses.

#### Definition and prevalence of persons living with disabilities

According to CDC, a "disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions)." The World Health Organization describes three dimensions of disability: impairment in body structure or function, activity limitation (e.g., seeing, hearing, walking), and participation restrictions in normal daily activities.<sup>1</sup> There are over 61 million people living with disabilities in the United States, accounting for more than 27% of the U.S. population or 1 in every 4 persons.<sup>2</sup> The population of people with disabilities is expected to grow with increasing rates of chronic medical conditions and aging. The most common types of disabilities are cognitive (12.8%) and mobility (12.1%), followed by disability affecting one's ability to live independently (7.2%), hear (6.1%), see (4.8%), or perform self-care (3.8%). Many people have multiple disabilities.<sup>3</sup>

#### Health disparities experienced by persons with disabilities

There is robust evidence that, compared to their non-disabled peers, persons with disabilities have higher prevalence of some diseases; higher rates of morbidity, mortality, and of some risk factors for poor health; and lower rates of receiving preventive care. They also experience access and physical barriers to high quality health care, report lower satisfaction

with care, and are subject to stigma, biases, and ableism. Below are examples of some of the topic areas from the literature that document disparities experienced by people living with disabilities.

### **Chronic disease and risk factors for poor health**

Adults with disabilities are more likely than those without disabilities to report having fair or poor health (40.3% vs. 9.9%)<sup>4</sup> and have higher rates of obesity, smoking, physical inactivity, diabetes, and heart disease.<sup>5-8</sup> Studies document higher prevalence of some cancers and higher cancer specific mortality among persons living with disability compared to their non-disabled peers. Pregnant women experience poorer quality maternity care and are more likely to have co-occurring conditions that increase their risk for complications.<sup>9</sup>

### **Preventive care**

Persons with disabilities are significantly less likely to receive preventive care,<sup>4</sup> including lower rates of mammograms, pap smears, and dental visits.<sup>10</sup>

### **Social drivers of health**

Having a disability is associated with an increased likelihood of having less than a high school education, lower likelihood of employment,<sup>11</sup> an increased likelihood of having an annual income less than \$15,000, and inadequate access to transportation.<sup>4,12</sup>

### **Access to care**

Among working age adults with disabilities, 1 in 3 do not have a regular health care provider and have unmet health care needs because of costs, and 1 in 4 have not had a routine check-up in the past year.<sup>13</sup>

### **Accessible medical and diagnostic equipment**

Persons living with disabilities experience barriers to timely, high-quality care due to lack of accessible medical facilities and examination equipment (e.g., exam tables, weight scales), and lack of language interpreters and individualized accommodations.<sup>14</sup>

### **Satisfaction with care and communication**

Persons living with disabilities are more likely to be dissatisfied with quality of care, access to specialists, follow-up, ease of getting doctors,<sup>15</sup> and physician communication.<sup>16</sup>

### **Stereotypes, stigma, bias, ableism**

Persons living with disabilities face barriers related to common misconceptions, stigma, and attitudes among providers.<sup>17</sup> Clinicians often have ableist attitudes toward their colleagues and patients with disabilities. In a nationwide survey, only 40% of physicians reported feeling very confident about their ability to provide the same quality of care to patients with disabilities as their other patients,<sup>18</sup> only 56.5% strongly agreed that they welcomed patients with disabilities into their practices, 82.4% of the physicians surveyed rated the quality of life of persons with disabilities as worse than those without disabilities, 18.1% agreed that the health care system often treats patients with disabilities unfairly.

In focus groups, many primary care and specialist physicians expressed explicit bias against persons with disabilities and reported strategies for discharging them from their practices. “Physicians raised concerns about the expense of providing physical and communication accommodations, including insufficient reimbursement for physicians’ efforts and competing demands for staff time and other practice resources.”<sup>19</sup>

A 2004 qualitative study of people who were deaf or hard of hearing identified that clinicians may believe that people with hearing loss have low intelligence, and thus, may disrespect their perspectives.<sup>20</sup>

## Summary key points for state of the science

Based on CDC’s health disparities definition, the brief PubMed literature reviews, and presentations by researchers and advocates on disabilities (see Appendix B), the following key points were summarized by the committee:

- Persons with disabilities often may have higher prevalence of morbidity and all-cause mortality, and experience access and physical barriers to high quality care.
- Persons with disabilities experience stigma, bias, and discrimination (e.g., ableism).
- Persons with disabilities experience social disadvantage and marginalization.

## Charge #2. Provide input on gaps, research needs, and strategic opportunities for health disparities research with an intersectional lens

### Scientific gaps

The committee identified several gaps that should be addressed to advance the study of disparities among persons living with disabilities. One significant gap revolves around the plethora of definitions of disability found in the research literature, as well as the numerous types of disability. Disability can be related to conditions that are present at birth and may affect functions later in life, including cognition (memory, learning, and understanding), mobility (moving around in the environment), vision, hearing, behavior, and other areas. Disability can be associated with developmental conditions that become apparent during childhood (e.g., autism spectrum disorder, attention-deficit/hyperactivity disorder or ADHD). Disability can be related to an injury (e.g., traumatic brain injury, spinal cord injury). Disability also may be associated with a longstanding condition (e.g., diabetes) that can cause a disability, such as vision loss, nerve damage, or limb loss. Finally, disability can be progressive (e.g., muscular dystrophy), static (e.g., limb loss), or intermittent (e.g., some forms of multiple sclerosis).<sup>21</sup>

Another key gap is the lack of research that applies an intersectional lens to examine and address the health and well-being of and health care for persons living with disabilities. When aggregating individuals’ disability status, functional impairment, and social determinants of health with multilevel factors, the experience of persons living with disabilities can be grossly complicated across the lifespan. Even still, interventions are largely focused on older adults and neither integrate social care and community engaged interventions into health care delivery models nor adapt clinical care guidelines.<sup>22</sup> Existing research tends to be clinically focused (e.g., health care service provision), targeting specific diagnoses among populations with health disparities (e.g., racial and ethnic minority groups, communities that are underserved, sexual and gender minority groups, people with limited English proficiency) rather than studying the intersectionality of various conditions, characteristics, and/or identities associated with health disparities. For example, there is a dearth of research on pregnant persons with disabilities, which would inform appropriate clinical practice



guidelines as well as improve understanding of related health and risk behaviors.<sup>23,24</sup> There is also limited study and interventions focusing on within and between group differences in multiple, minoritized groups and the range of factors that influence overall physical and mental health functioning and outcomes. Therefore, targeted research is needed to better understand the range of factors, interactions, and causal pathways influencing health disparities experienced among persons with disabilities, and to develop actionable strategies to mitigate their impact on health outcomes and quality of life across populations and domains of influence (excerpted from [NIMHD Scientific Concept on Health Disparities Experienced Among Persons Living with Disability](#)—Wonnum, Aviles-Santa, Banyas, Barksdale, Doose, Herren, Linares, Marshall, Mujuru, Oladeinde, Sidhu, September 2022).

## Research needs and strategic opportunities

### Clarification of scope of disparities among persons living with disabilities

Given the heterogeneity of the definition of disability and the many ways that people experience disability across the life course, research is needed to establish which populations with disabilities are more at risk of experiencing health disparities. Disability types vary in prevalence and in how they are associated with health disparities. In the United States, disabilities in mobility and cognition are the most reported.<sup>25</sup> Certain subtypes of disabilities (physical vs. cognitive or intellectual) are more commonly studied and may contribute more to disparities, depending on the variables of interest.

### Intersectionality

Generally, disability disproportionately affects some groups, including those known to experience health disparities: American Indian or Alaska Native people, Black or African American people, Asian people, Native Hawaiian or Pacific Islander people, Hispanic or Latino people, women, sexual and gender minority groups, people with lower socioeconomic status, and people living in rural areas. This intersectionality is associated with higher rates of poor health among persons with disabilities compared to their non-disabled peers within these groups. Rural residents with disabilities face additional barriers related to finding physicians with appropriate expertise who are willing to see them and have medical and diagnostic equipment to accommodate limitations.<sup>26</sup>

### Etiology

Research is needed on the etiology and impact of disparities as well as methods to mitigate their negative effects in persons with disabilities. Investigating the etiology of disparities in this population is essential to uncover the underlying factors and understand root causes. This can lead to targeted interventions and policies. For example, research may reveal that disparities in access to health care services stem from structural barriers, discrimination, or lack of appropriate accommodations. Such research findings will inform the development of evidence-based policies to reduce these barriers. Studying the impact of disparities can help quantify the negative effects on the health of persons with disabilities.

## Summary of NIH investment in health disparities research among persons living with disabilities

### NIMHD actions to date

- **In September 2022, NACMHD approved the following scientific concept: “Health disparities experienced among persons living with disabilities.”** An NIH-wide Notice of Funding Opportunity (NOFO) announcement development is underway and will apply an intersectional lens with NIMHD’s traditionally identified communities of

focus. During that same council meeting, the NIMHD Director established a working group to address the topic of the current report. The group met monthly for about 1 year and produced the present report.

- **NIH portfolio analysis of funded research related to persons living with disabilities (2018–2022).**

Methods: NIMHD staff searched the NIH internal database of grants (IMPAC II) for fiscal years (FYs) 2018, 2020, 2021, and 2022. They included all NIH extramural awards (including supplements) organized by administering/primary Institutes and Centers (ICs). Awards were indexed by one or more of the Research, Condition, and Disease Categorization (RCDC) terms, with index weight set at  $\geq 60$  to minimize false positives. A sensitivity analysis was also conducted with weights set at  $>40$ . They included as variables terms indexed in the RCDC system at NIH.

Results: Between 2018 and 2022, total funding for disability-related awards across 25 NIH ICs ranged between 6.6 to 11.8 billion dollars. The most common funding mechanism for funding disability-related research was R01-equivalent (N=7,496 awards, \$4.7 billion) and other research project grant (RPG) awards (N=2,345 awards, \$1.17 billion). The most prevalent conditions in this portfolio included brain disorders, aging, mental health, neurodegenerative conditions, acquired cognitive impairment, dementia, Alzheimer's, intellectual and developmental disabilities, cerebrovascular conditions, and rare disease.

- **Portfolio analysis of funded NIH research related to health disparities among persons living with disabilities.**

A portfolio analysis of funded projects across all ICs within NIH (2018–2022) was presented to NACMHD for development of a potential funding announcement for research on the intersection of health disparities and disabilities in September 2022. The analysis revealed 292 projects related to disability conditions and health disparities (see Table 1). Projects related to pain, cancer, and HIV research were excluded, because the primary goal of many of these studies was not on a disability, and because a diagnosis of any one of these conditions is not necessarily indicative of a qualifying disability. The NIMHD analysis of funded research on persons living with disabilities yielded a total of nine funded grants on varying topics (e.g., pediatric or geriatric conditions, co-occurring obesity, biomedical technological interventions). An analysis of projects within the National Institute of Child Health and Human Development's (NICHD) National Center for Medical Rehabilitative Research found 37 funded projects, of which three were co-funded by NIMHD. Table 2 describes a focused analysis of projects within six Institutes (National Institute of Mental Health [NIMH], National Institute on Aging [NIA], National Eye Institute [NEI], NIMHD, NICHD, and National Institute on Deafness and Other Communication Disorders [NIDCD]) that emphasizes the study of health disparities related to disability impairments—vision, hearing, cognition, development, and independent living.

**Table1: Disabilities and Health Funded Disparities Research (FY2018-2022)**

| Project Focus                      | No. of Projects |
|------------------------------------|-----------------|
| Disability conditions (all ICs)*   | 292             |
| Disability conditions (NICHD)**    | 37 (12.7%)      |
| Disability and disparities         | 9 (3.1%)        |
| SMI & disparities***               | 11 (3.8%)       |
| Disability & finances/housing/food | 28 (9.6%)       |
| IDD & finances/housing/food        | 1 (0.3%)        |

\*Excludes HIV, cancer, pain

\*\*Co-funded w/NIMHD \*\*\*Co-funded NIMHD& NIMH"

**Table2: Focused Review of Science of Six Institutes (NIMHD, NICHD, NIDCD, NIMH, NIA, NEI)**

| Type of Science               | No. of Projects |
|-------------------------------|-----------------|
| Clinical trials/research      | 48 (40.7)       |
| Bioinformatics/engineering    | 17 (6%)         |
| Behavioral                    | 14 (5%)         |
| Health Services Research      | 12 (4%)         |
| Mechanisms of disease         | 8 (3%)          |
| Translational - Translational | 10 (3%)         |
| Basic Research                | 7 (2%)          |
| Epidemiological               | 2 (0.6%)        |
| <b>Total</b>                  | <b>118</b>      |

### Charge #3. Assess the alignment of persons living with disability with currently designated health disparity populations

#### Minority health and health disparities: Definitions and parameters

Definitions of the terms “minority health” and “health disparities” have evolved as the research fields have grown and interacted with the full spectrum of scientists. Initially, the definitions were intertwined, as the researchers doing this important work have bridged both fields, and the assumption was made that minority populations always had health disparities. For NIH, this underscores the need to separate the science of minority health—which focuses on the health of racial and ethnic minority communities—and the science of health disparities, which focuses on differences in health outcomes for defined populations that are disadvantaged and worse than the White reference population. There is a clear overlap, since for many conditions, minority populations have well-defined health disparities compared with the White population in the United States. However, creating some separation of these disciplines may prove beneficial in enabling each field to make greater, independent strides. Over the course of FYs 2015 and 2016, NIMHD undertook a process across NIH to revise the definitions for minority health and health disparities.

#### Minority health definition

Minority health refers to the distinctive health characteristics and attributes of racial and/or ethnic minority groups, as defined by the U.S. Office of Management and Budget (OMB), that can be socially disadvantaged due in part to being subject to potential discriminatory acts.

#### Minority health populations

NIH uses the racial and ethnic group classifications determined by OMB in the Revisions to Directive 15, titled “Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity.” The racial and ethnic minority groups defined by OMB are American Indian or Alaska Native, Asian, Black or African American, and Native Hawaiian or Pacific Islander. The ethnicity used is Hispanic or Latino.

Although these five categories are minimally required, the mixed or multiple race category should be considered in analyses and reporting when available.

Other NIH efforts that support Tribal Nations can be found in the [NIH Strategic Plan for Tribal Health Research FY 2019-2023. \(PDF 1.1 MB\)](#)

Self-identification is the preferred means of obtaining racial and ethnic identity.

### Populations with health disparities

For NIH, populations that experience health disparities include:

- Racial and ethnic minority groups (see [OMB Directive 15](#)).
- People with lower socioeconomic status.
- Underserved rural communities.
- Sexual and gender minority (SGM) groups.

Other NIH efforts that support SGM groups can be found in the [NIH FY 2016–2020 Strategic Plan to Advance Research on the Health and Well-being of Sexual and Gender Minorities](#). (PDF 2.3 MB)

### Alignment of persons living with disabilities with currently designated health disparity populations

As a committee, we heard special presentations by Drs. Louis Sullivan (Secretary of Health and Human Services 1989–1993) and Spero Manson (Director of the Center for American Indian and Alaska Native Health, Colorado School of Public Health) on the history, original purpose, and mission of NIMHD. As the Secretary of Health and Human Services, in 1990, Dr. Sullivan directed the establishment of the Office of Minority Programs in the NIH Office of the Director. The Institute, which evolved starting in 1993 from an Office of Minority Health to a Center of Minority Health and now an Institute (2010), has as its core mission—to advance the science of minority health and health disparities within NIH. As noted above, current NIH-designated U.S. health disparity populations include American Indian/Alaska Native, Asian, Black/African American, Hispanic/Latino, Native Hawaiian/Pacific Islander, sexual and gender minority groups, populations that are socioeconomically disadvantaged, and rural populations that are underserved. To help to inform our recommendations, we examined the alignment of people with disabilities with these groups as outlined below.

### Presence of health disparities

All currently designated health disparity populations experience disparities in their health, health care, and/or health outcomes (compared to a reference group). Based on a commonly used definition, including by NIH, a health disparity is a “health difference that adversely affects disadvantaged populations based on one or more of the following: Higher incidence and/or prevalence and earlier onset of disease; higher prevalence of risk factors or clinical measures in the causal pathway of a disease outcome; higher rates of condition specific symptoms, reduced global daily functioning, or self-reported quality of life; premature or excessive mortality from diseases where population rates differ; and greater global burden of disease using a standardized metric.<sup>27</sup> Based on the review of the literature, in comparison to their non-disabled counterparts, some persons with disabilities experience health disparities as evidenced by higher prevalence of some diseases (e.g., heart disease, cancer), higher prevalence of risk factors for disease (e.g., obesity, tobacco use), reduced global functioning and poorer self-reported health and quality of life, and shortened survival from some conditions (e.g., cancer). The committee recognizes that given the heterogeneity of conditions which lead to disability, there is variability in the presence and extent of disparities for persons with different types of disabilities.

### Decreased access to care

Current health disparity populations experience decreased access to health care (compared to a reference group). Based on the review of the literature, persons with disabilities also face challenges in accessing health care. What may be potentially important to consider about persons with disabilities is that issues of access to care are in part related to issues of accessibility—that is, absence of medical and diagnostic equipment to accommodate their disability, absence of providers familiar with some conditions, and absence of other accommodations in health care settings (e.g., support for patients who use wheel chairs for mobility, communication accommodations for those with impaired vision and hearing).

### Stigma, discrimination, stereotyping, and bias

Current health disparity populations experience stigma, discrimination, stereotyping, and bias in health care settings that impact the quality of health care delivery and may contribute to disparities. We found some evidence in our review of the literature that persons with disabilities also experience stigma, discrimination, and bias. In addition, persons with disabilities experience ableism, which is defined as “discrimination in favor of [able-bodied](#) people.” Ableism refers to attitudes in society that devalue and limit the potential of persons with disabilities—attitudes that are clearly causative in subjecting persons with disability to disparities in health care and health outcomes.

### Demographic group

A demographic group is a subset of the general population. Current health disparity populations are designated as demographic groups for which data are routinely collected. As a demographic category, disability is an attribute with which individuals may broadly identify, similar to race or gender. Over the years, there have been increasing calls to collect disability status as part of routine demographic information.

### Related medical condition, disease, or disorder

Building on the definition and concept of health disparities, an increasingly popular term is health inequities—defined by most scholars as avoidable differences in health outcomes between groups of people that are **not** due to underlying medical conditions, but from differences that are linked to a history of social, economic, or environmental disadvantages.<sup>28</sup> Currently designated health disparity populations experience health inequities based on this definition, as their disadvantage is not due to an underlying medical condition. Many of these populations (e.g., racial and ethnic groups, SGM groups) are fundamentally social categories or in the case of race, a social construct created for the sole purpose of discrimination. In contrast, “disability” as a population has different meanings in different contexts. In some contexts, it is an impairment that follows as a consequence of a medical condition to the body (e.g., diabetes, Alzheimer’s disease). In other contexts, disability is a cultural and social identity because of the impact of disability on how persons can interact with the environment and access health care. However, in contrast to currently defined health disparity populations, disability results from a medical condition or biological process (congenital or acquired), which leads to physical, cognitive, and/or social limitations. Persons that are affected may or may not be impacted by discrimination based on their identity as a person with that disability. In other words, while individuals with disability face discrimination due to their identity, such identity may not be the primary driver of their health disparity.

### Considerations for making persons living with a disability a health disparity population

Based on the work and deliberations of the committee, we believe the following issues are important considerations in designating persons with disability as a health disparity population.

**1. Making a designation of health disparity population to persons living with disabilities may increase research related to disparities.** As demonstrated from the portfolio analysis (page 12), there is already significant investment in this area cumulatively across NIH ICs. However, it is possible that being labeled as a health disparity population could further increase resources and research investment. In addition, the designation may lead to a greater focus on areas that have received less attention to date, including (1) research related to the prevalence, etiology, and consequences of bias, discrimination, and identity across cognitive and medical conditions; (2) research to delineate which conditions among persons living with disabilities are associated with poorer quality health and health care and why; and (3) research examining how the intersection of disability with current health disparity populations impacts health outcomes. In addition to the potential for increase in NIH-funded research, some of the disability advocates that we heard from during our deliberations suggested that the designation could lead to new funding opportunities and greater investments in research related to persons with disability by non-NIH funding sources.

**2. Designating persons living with disability as a health disparity population may lead to greater inclusion of researchers with disabilities and persons with disabilities as participants in research studies.** As has been shown for other populations that face disparities, having persons with a shared experience participate in the research enterprise often leads to meaningful research that is both representative of the population under study and accessible to the general population.<sup>29</sup> Furthermore, having researchers from populations with disability can often facilitate recruitment of persons living with disability into research studies and create a social capital infrastructure that is built on trust and reciprocity due to the shared experience of disability.<sup>30</sup>

**3. Designating persons living with disability as a health disparity population may lead to additional efforts to develop a comprehensive strategy and create a centralized infrastructure to address the needs of this population.** Below, we recommend creating a centralized infrastructure (Office of Disabilities Research) to direct research related to persons living with disabilities across NIH. Designating persons living with disability as a health disparity population could serve as an initial step in this process and potentially ignite efforts to quickly establish an appropriate infrastructure to inform research needs and direction. In addition, we heard from advocates on disability that this designation may lead other federal and non-federal agencies to increase support to address bias and discrimination experienced by persons living with disabilities and to increase resources that address social drivers of health disparities in this population.

**4. Designating persons living with disability as a health disparity population may dilute funding and other resources at NIMHD that support research for currently designated health disparity populations.** The current budget for NIMHD is 525 million dollars. The FY22 funding success rate is 17.4%, which is significantly lower than many of the other ICs that fund research related to persons with disabilities. The addition of the population with disabilities would be expected to lead to a greater number of applications with potentially lower funding success rates. This is important because there is no question that additional efforts are needed to address disparities in currently designated health disparities populations. A recent report in *JAMA Network* showed that over a 22-year period, excess mortality and years of potential life lost among the Black population in the United States has far exceeded the White population. Sadly, “after a period of progress in reducing disparities, improvement stalled, and differences between the Black population and the White population worsened in 2020.”<sup>31</sup> Similar trends have been documented for disparities for rural health<sup>32</sup> and people with low socioeconomic status.<sup>33</sup> With the addition of persons living with disabilities as a health disparities population, the federal government must guarantee that the funding and staffing of NIMHD would be increased appropriately to support the addition of disability as a disparities population, such that NIMHD’s focus on the existing disparity communities is not only fully protected but supported to grow even stronger. This is particularly important as at least 27% of the U.S.

population suffers from a disability, which means that a large percentage of NIH disparity funding could be shunted toward these subpopulations.

Although any NIH Institute can support disparities research, NIMHD has a specified mission to lead scientific research to improve minority health and reduce health disparities. When addressing the limited budget and staff of NIMHD, there is concern for an overwhelming influx of applications for study of the broad and heterogeneous populations of persons with disabilities. It should be considered that making this designation and having NIMHD shepherd the resources could reduce accountability of other ICs to fund disability research. Also, given that NIMHD is tasked with promoting and supporting the training of a diverse research workforce, including currently designated populations that are underrepresented in medicine,<sup>34,35</sup> this designation could dilute efforts to train such scholars, potentially exacerbating the disparities that have been in place for decades.<sup>31</sup> Taken together, there is the risk of mission creep and loss of focus at NIMHD on the currently designated minority populations facing health disparities.

**5. There is a lack of alignment in the designation of persons with disabilities and other already designated disparity populations that must be recognized and examined further.** As noted above, although there is increasing recognition of the social, environmental, and cultural contexts of disability, persons with disability experience impairments that can lead to disparities in health care access and outcomes (compared to their non-disabled counterparts) because of a congenital or acquired **medical condition**. This is not true of any of the currently designated health disparity populations, which are defined by social and demographic characteristics without dependence on the presence of a medical condition. For racial and ethnic groups and SGM groups at least, their identity often leads to health disparities. This is a potentially important distinction between individuals living with disability and other health disparity groups. Individuals from racial and ethnic minority groups and SGM groups suffer primarily because of their **social identity**. While individuals with disabilities suffer from discrimination, ableism, and stigma—often due to **medical limitations** (albeit unfairly and cruelly)—it is not solely the result of their social identity in every case. This definition of disparity represents a new conceptualization that goes beyond the current NIH definition. While some may argue that evidence of poorer health compared to a reference population should by itself be enough for the designation, and that the presence or absence of a medical disorder has not been featured prominently in descriptions of health disparities populations as described by NIH, we believe that this is an important consideration for two reasons.

First, it is important to consider the evolution in language and conceptualization related to understanding and describing health differences across populations. As noted above, health inequities, an increasingly popular term, is defined as avoidable differences in health outcomes between groups of people that are **not due to underlying medical conditions**, but from differences that are linked to a history of social, economic, or environmental disadvantages. Second, considerations of expanding health disparities populations to include a group with an impairing **medical condition** must include some deliberation about the extent to which other groups may be similarly eligible for the designation. That is, other groups with medical conditions experience poorer health compared to the general population or those without the corresponding condition. For example, people with severe obesity experience poorer health than those who are non-obese—including higher rates of heart disease, some cancers, diabetes, and higher mortality—and face stigma, discrimination, and bias.<sup>36</sup> Similarly, people with chronic obstructive pulmonary disease have higher rates of cardiovascular disease and mortality compared to the general population and report experiences of stigma and discrimination.<sup>37-39</sup>

**6. Although CDC and other organizations have definitions of disability, it is unclear how individuals with various mental health conditions would or would not be included under the current rubric of disability.** Would individuals with learning disabilities, autism spectrum disorder, and affective conditions fall within this new disparity group? For example, having anxiety disorder limits one's ability to interact and experience activities of daily living. Moreover, it is

unclear which subgroups within the populations with disability would receive priority consideration based on the health disparities population designation. Based on evidence of heterogeneity in the presence and extent of health and health care disparities, as well as the experience of stigma and discrimination, the committee asked experts and advocates on disability to identify the subgroup of persons with disabilities that should be prioritized. Research is needed to identify subgroups at greatest risk for poor health outcomes and to inform or guide a research agenda in the face of funding limitations.

**The committee makes the following recommendations, which we believe can have an immediate impact on increasing research and establishing a research infrastructure with a focus on persons living with disabilities.**

**1. The committee recommends that strong consideration be given to establishing an Office of Disability Research (ODR) to coordinate NIH disabilities research.** The office could be patterned after other successful models, such as the Office of Minority Health, and the Sexual and Gender Minority Research Office. Like the SGM Office, ODR would conduct activities to inform priority setting and research agendas, collaborate with NIH ICs to disseminate relevant information, and develop initiatives and funding opportunities to support research on persons living with disabilities. The office could lead deliberations to inform next steps based on identified needs, gaps, and opportunities, including potentially establishing an Institute for Disabilities Research in the future via a similar process that led to the establishment of NIMHD.

**2. The committee recommends that starting immediately, NIMHD and others incorporate a greater emphasis on the intersection of disability and other conditions.** NIMHD should consider incorporating a greater research focus on the intersection of disability and other populations with health disparities. NOFOs should be developed to study intersectionality, specifically persons with disabilities who are also members of another health disparity population (by NIMHD) or persons with disability who have co-existing chronic conditions (by other ICs). These studies could examine the added disadvantage associated with having a disability, focus on identifying multi-level causes of poor health and health care outcomes, and develop and test multi-level interventions. Such studies are important given current evidence of the prevalence of disability in health disparity populations and increased prevalence of some chronic conditions in persons living with disabilities. Of note, NIMHD approved the concept titled “Health Disparities Experienced Among Persons Living with Disabilities” at the September 2022 Council Meeting, and a NOFO announcement development is underway. In addition, other ICs could consider NOFOs that focus on the intersection of disability with diagnoses or conditions corresponding to their populations of interest. For example, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) could examine health care experiences and outcomes for persons with chronic kidney disease and disability. NICHD could issue NOFOs examining the intersection of disability and maternal health. Other ICs can support research on disparities in their relevant disease groups; for example, the National Cancer Institute could focus on cancer, NIDDK could focus on obesity and diabetes, and the National Heart, Lung, and Blood Institute could focus on heart disease and stroke.

It is also recommended that NIH develops NOFAs as supplements to existing funded research. To stimulate research in a particular area of focus (e.g., artificial intelligence, bioethics, stigma), NIH frequently issues requests for supplement applications to funded RPGs and other grants (e.g., cooperative agreements, program project and center grants). A similar process calling for supplement applications related to the experience of persons living with disabilities could stimulate additional research and funding in this area.

**3. The committee recommends that ICs should undertake a portfolio analysis to identify gaps (which conditions have received little or no attention?) in the study of certain disabling conditions and issue NOFOs to stimulate research in those areas.** NIH should partner with other organizations to encourage greater recognition, funding, and



support for persons living with disabilities. These organizations could include others that fund research (e.g., AHRQ, Patient-Centered Outcomes Research Institute, CDC) or lead work to improve policy or advance health care payment models to improve care (e.g., capability maturity model integration). In addition, NIH should partner with organizations to increase provider training related to the care of persons living with disabilities (e.g., Association of American Medical Colleges), increase enforcement of existing regulations—which may improve care of persons living with disabilities through greater accessibility of medical and diagnostic equipment—and create and make available a standardized set of measures for determining disability status of study participants, measuring the quality of health care delivery, and assessing patient-centered outcomes directly relevant to the disabilities community.

## In summary

This report concludes the work of this committee. We urge the government to move quickly to develop a mechanism to organize, oversee, and stimulate research on disparities experienced by persons with disabilities. This requires a commitment of additional funding so as not to reduce support for research on currently designated health disparities populations.

We close this inquiry by noting that while multiple experts representing people with disabilities gave testimonies to the committee, the committee itself did not include anyone who self-identifies as a person with disability. We recommend that any further working groups, committees, or leadership in this area include people with lived experience with disabilities and those with specific research expertise in this area.

## Appendix A

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## Appendix B

### Agendas: Meeting Schedule, Agenda Topics, and Speakers

| Date   | Agenda Topics   |
|--|---|
| November 7, 2022<br>4–5:30 p.m. (virtual meeting)                | Overview and charge   |
| December 13, 2023<br>10 a.m.–12 p.m. (virtual meeting)           | Review of requested materials and discussion<br><br>A special presentation to the NACMHD Working Group: Andres J. Gallegos, Chairman; Ana Torres Davis, J.D., Senior Staff Attorney   |
| February 28, 2023<br>10 a.m.–12 p.m. (virtual meeting)           | Review of materials and discussion<br><br>A Special presentation to the NACMHD Working Group:<br>Disability as a Health Disparity Population, Alison Barkoff, Acting Administrator and Assistant Secretary for Aging; and Anjali J. Forber-Pratt, Director, National Institute of Disability, Independent Living & Rehabilitation Research, Administration for Community Living<br><br>Defining Disability: Methodological and Theoretical Contexts for Consideration, Megan Henly, Project Director, Advanced Rehabilitation Research Training (ARRT) on Employment Disability Statistics and Demographics Rehabilitation Research and Training Center (StatsRRTC), University of New Hampshire Disability and Health Program<br><br>Disability and Health Disparities: Overview, Lisa I. Iezzoni, Professor of Medicine, Harvard Medical School |
| March 28, 2023<br>10–11 a.m. (virtual meeting)                   | Review materials and discussion   |
| May 8, 2023. 10–11 a.m. (virtual meeting)                        | Review materials and discussion<br><br>A special presentation to the NACMHD Working Group:<br>Louis W. Sullivan, M.D., Secretary, U.S. Department of Health and Human Services, 1989–1993, President Emeritus, Morehouse School of Medicine<br><br>Spero Manson, Ph.D., Distinguished Professor, Director, Centers for American Indian & Alaska Native Health (CAIANH), Department of Community & Behavioral Health, Colorado School of Public Health   |
| May 22, 2023 (in-person meeting)                                 | Review materials and discussion; presented preliminary report to the NIMHD Director and council during closed session   |
| June 26, 2023<br>2–4 p.m. (virtual meeting)                      | Review recommendations and determine each committee person’s view on issue  |
| August 1, 2023, and August 22, 2023. 12–2 p.m. (virtual meeting) | Final meeting before meeting with the NIMHD Director; reviewed recommendations, discussed draft report  |